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RESOURCING AND TRAINING HEAD AND NECK CANCER NURSE SPECIALISTS TO DELIVER A SOCIAL REHABILITATION PROGRAMME TO PATIENTS.

Volume Two.

Alexandra Clarke

Doctor of Clinical Psychology

Department of Psychology

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CHANGING faces

A BETTER FUTURE FOR
FACIALLY DISFIGURED PEOPLE

SOCIAL REHABILITATION TRAINING AFTER HEAD AND NECK CANCER

A resource for health professionals

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written by
Alex Clarke MSc AFBPsS SRN
Chartered Clinical Psychologist

produced by
Changing Faces
1-2 Junction Mews, London W2 1PN
Tel: 0171 706 4232 Fax: 0171 706 4234
e-mail info@faces.demon.co.uk

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PART ONE: FACING UP TO CHANGE – THE CHALLENGE OF SOCIAL REHABILITATION

Section 1 – Aims and rationale of the Changing Faces head and neck cancer Social Rehabilitation Training (SRT) programme

1.i What is the SRT programme?

This initiative is a new development from *Changing Faces*, which applies our problem-solving skills approach to the post-operative care of patients with head and neck cancer. It aims to provide specialist head and neck nurses and other health professionals with the knowledge and resources to implement social rehabilitation training for patients who have undergone surgery, so that they can equip patients with the skills that they need to resume the activities of everyday life.

1.ii Background to the approach

Since 1992, when the charity was formed, *Changing Faces* has worked to provide a better future for people who are visibly disfigured, through its direct work with patients, support of health professionals, teachers and employers, and through awareness raising via the media. The charity's commitment to underpinning all its work with research, means that we have been able to evaluate the impact of our work and identify those for whom our approach has long-term benefits.

Visible difference, particularly facial disfigurement, can cause major problems in areas of social interaction. People who look different incite curiosity which can manifest itself as staring, comments, discrimination in the workplace, relationship problems etc. Self-esteem, in a society which overvalues appearance, can plummet, and many people develop high levels of social anxiety leading to avoidance of social situations. Depression can be high in a group which feels isolated, unable to gain employment, and identifies itself as having fewer opportunities than those who are visually non-distinctive.

Whilst everyone who looks different can expect some level of intrusion, staring etc., some people develop very positive coping strategies for dealing with other people, and it is through understanding how people who cope well achieve this that *Changing Faces* has developed a programme of training for those who are less successful.

Basically, managing being visibly different means being prepared to take the initiative in social situations, dealing with embarrassment and uncertainty in others by taking the lead and putting others at ease. In essence, those who have good social and problem-solving skills have fewer problems than those who do not. Putting a training package together to teach those who do not shows both immediate and long-term benefits in terms of lower anxiety and the ability to take part in the ordinary activities of day to day life.

Teaching these problem-solving skills can be delivered either in one-to-one settings or in groups, and has been equally effective in patients with long-term or recent disfigurements, those with minor or severe disfigurements, and across a wide range of medical conditions.

1.iii Why are problem-solving skills necessary for patients with head and neck cancer?

The specific rehabilitation problems of patients who have treatment for head and neck cancer are reviewed in Section 2, but in summary, this is a population of people for whom the effects of life-saving surgery can cause not only severe disfigurement, but considerable dysfunction. While some patients cope well with 'picking up the pieces', quality of life measured months or years after surgery has been reported as so low for some patients, that the validity of surgical intervention which leads to such devastating personal loss has been questioned.

Research studies have been unanimous in identifying this population as one with psychosocial problems and in need of support. However, the way in which support can be provided and the specific content of Outreach programmes has yet to be defined. Proposed solutions include the provision of informed supportive counselling, more patient support groups, provision of written information and coping skills training.

Coping skills training is based on psychological models which stress the importance of how a problem is perceived as well as how behaviour can be changed. So far, despite the potential usefulness of the approach, there has been no attempt to design and evaluate this kind of intervention in this population in a comprehensive way. This SRT programme takes up that challenge, by expanding the *Changing Faces* approach to facial disfigurement to encompass issues of dysfunction such as eating and speech. The rationale for this approach is based on the evidence of patients' self report describing the psychological *consequences* of dysfunction – i.e. social anxiety and embarrassment – in very similar terms to the consequences of disfigurement.

1.iv SRT programme structure

Since the aim of the programme is both to inform and to resource the health professional using it, the programme is designed in three main parts.

I. Part One consists of a review of the evidence from recent studies of the main problems of these patients and the challenges for successful rehabilitation. The problem-solving skills approach is described.

II. Part Two consists of a manual or 'how to do it' section. A six-session group training programme for patients and relatives is set out. These sessions teach basic social skills and problem-focused strategies using group exercises, role play and discussion. Patients and relatives work as pairs so that relatives can learn more about the common difficulties of rehabilitation and specific strategies for support. Training is backed by specially developed patient literature and video which is designed to be used in the training sessions but can also be used independently.

III. Part Three consists of graded exercises which guide patients through common social situations and allow them to apply the skills that they have learned.

1.v How to use the SRT programme

The programme has been designed to be used flexibly to accommodate the needs of health professionals working with very different resources, and according to patient need.

Health professionals have the resources to do any of the following:

- Use the programme as a simple information source for themselves and their patients.
- Set up a six-session group training programme with patients and their carers using the session guides and exercises provided.
- Select from the session guides to provide a shorter training programme.
- Use some of the exercises or resources within the context of a more traditional support group.
- Use some or all of the exercises in one-to-one settings instead of in groups.
- Use the additional resources (booklets and videos) on their own.

1.vi Who is the SRT programme for?

Managing social situations can be challenging for anyone who is stigmatised either by appearance or behaviour. Screening out those who are considered particularly at risk cannot be based on the size or location of disfigurement.. For this reason, *Changing Faces* offers support to *everyone* who is visibly different.

It is suggested that some form of social rehabilitation be offered routinely to all patients. In its minimum form this might be offering written information or watching the REACH OUT video. For other people, targeting specific situations using the handouts in Part Three would be appropriate. Others may choose to attend the six session course. The flexibility of the programme recognises both the needs of different patients and the range of patient services available to this group.

For some patients, this course will not be enough, and guidelines for identifying those people who should be referred on for specialist psychological or psychiatric help are given in Part Four.

1.vii Is the SRT programme effective?

Changing Faces is evaluating the programme using both quantitative and qualitative measures. These measures are included in the Appendix so that individual health professionals can monitor the effectiveness of their work with patients in their own units.

Section 2 – The Psychosocial Impact of Head and Neck Cancer

2.i Introduction

The impact of a diagnosis of cancer is an enormous one; the immediate threat to life followed by the trauma of medical investigation, and uncertainty about treatment issues and outcome all add together to make this one of the greatest fears within our society.

For the patient with cancer of the head and neck, the site of the disease has an additional impact .The face is our means of communicating with other people. We all look at faces when we are speaking and listening, developing a complicated signalling procedure which depends on eye contact, smiling etc. The process of speech articulation is clearly dependent on structures in the head and neck region. Cancer and the treatment for invasive disease can therefore have a major impact on the communication process.

Ingestion of food, chewing, swallowing, salivation are frequently affected, with profound implications for ensuring optimum nutrition, but also impacting dramatically on the social aspects of eating. Patients can be embarrassed about the difficulties of drooling or spilling food, using special utensils or straws. The interruption of what is an important social activity can have a big effect on self-esteem.

Finally, the face is also a primary determinant of our internalised body image or sense of who we are. Adapting to an altered body image is a long process which may involve grieving for lost looks; many patients describe the process as one of bereavement. Physical attractiveness is an important determinant of our expectations about how other people will judge us. First impressions are important in our image-conscious society, and adapting to disfigurement – even when minor – can be profoundly difficult.

First encounters are particularly stressful, staring and intrusions are commonplace, and social avoidance can rapidly develop as the simplest means of survival. Since physical attractiveness reinforces the sexual stereotype, patients may feel less feminine or less masculine and the expectation of no longer being sexually desirable is a major concern especially for younger patients. Simple barriers to sexual activity such as altered facial sensation and the ability to kiss a partner can cause enormous distress and yet have received very little attention in terms of investigating psychosocial sequelae and/or support.

2.ii Psychiatric morbidity

One strategy for investigating the impact of head and neck cancer on this patient group is to measure the psychiatric morbidity within the group and compare this with both the normal population and other groups of cancer patients.

The most common psychiatric disorder among cancer patients generally is a reactive anxiety usually combined with depression. Much of the research has been done with breast cancer patients, where it is estimated that 25–30 per cent of patients experience anxiety and depression at some stage which is serious enough to need treatment. (Carlsson et al 1994, Edwards 1997) Particular vulnerable stages have been identified including diagnosis, discharge and recurrence. (Bushkin, 1995)

Patients with head and neck cancer have not only an increased incidence but increased severity of anxiety and depression when compared with other groups. Incidence of suicide is seven times as high within this group compared with other cancer survivors, and there appears to be a relationship between this high level and problems of social interaction: eating, communicating and dealing with altered facial appearance. (Faberow et al 1971, Edwards 1997)

Other psychiatric problems arise as a result of premorbid conditions. Given that smoking and alcohol intake are known to be causal in this disease, there may be a higher rate of emotional or personality difficulties, anxiety and substance abuse which pre exist the disease and continue to cause problems, for example with compliance, post operatively. Breitbart and Holland (1988) give a good review of psychiatric problems within this group.

2.iii Psychosocial problems

In differentiating psychosocial problems and psychiatric problems, the aim is to draw a distinction between those conditions which fall within the DSM111 classification, recognised as abnormalities of mental health which may require medical intervention, and those problems which are essentially those of coping with profound change within a social environment.

Although the package of difficulties is often considered as a whole, it is useful to draw this distinction in order to look at alternative kinds of intervention at the rehabilitation stage.

Psychosocial difficulties are increasingly being described within a rather different research paradigm which attempts to measure quality of life. The impetus behind this research is the recognition that even where psychiatric conditions do not develop, the change in the patient's lifestyle is dramatic enough to raise moral questions about the ethics of treatment which causes such a profound reduction in the ability to participate in everyday activities. A number of scales have been developed, or are under development, which attempt to measure outcome in a way which will allow different surgical procedures to be compared and which point the way, hopefully, to more appropriate rehabilitation. (Bjordal et al 1994, Baker 1995)

There are enormous problems with measuring quality of life (see Gotay and Moore 1992, for review) since clearly, the only relevant person in describing this is the patient. Studies that use checklists completed by health professionals on the patient's behalf can completely miss the point. Even compiling a scale forces categories on the patient which may not be the relevant ones for him or her. However working with an entirely qualitative definition – quality of life is what the patient says it is- has its own problems in drawing comparisons within and between groups.

However, the quality of life research has been useful in highlighting the main areas of difficulty.

Baker (1995) has developed a functional status scale for measuring quality of life outcomes in head and neck cancer patients. This is a self report scale, reproduced here in full, as it is a good summary of the range of problems that may be experienced by patients post treatment.

1 Shoulder/ Upper body mobility with elbows straight

- I have full range of motion of both arms
- I can raise at least one arm above my head
- I can lift at least one arm to shoulder level
- I have difficulty lifting either of my arms to shoulder level

2 Chewing

- I seldom, if ever, have trouble chewing
- I have trouble chewing things like steak or raw vegetables
- I usually eat foods that do not require chewing
- I can only eat foods that do not require chewing
- I can only take liquid nourishment

3 Swallowing (1)

- I have no difficulty swallowing
- I have difficulty swallowing when I eat rapidly
- I choke or gag unless I concentrate on swallowing
- I usually choke on liquids
- I am unable to swallow liquids

4 Swallowing (2)

- I have no difficulty in swallowing
- I have difficulty moving food to the back of my throat
- I can swallow solids only by taking liquids with the food
- I can only swallow semisolid or pureed foods
- I am unable to swallow any foods or liquids

5 Drooling

- I do not have a problem with drooling
- I have problems with drooling when tired or sleeping
- I have trouble with saliva when I am speaking
- I drool most of the time
- I have a constant problem with drooling

6 Taste

- I have no problem tasting foods
- I only taste foods with strong odors
- I only taste foods with certain flavours
- I cannot taste foods
- I cannot taste or smell foods

7 Dry mouth

- I seldom have a dry mouth
- I wake up at night because my mouth is dry
- I drink fluids between meals to moisten my mouth. (Dry periodically)
- I moisten my mouth and throat frequently.(Dry frequently)
- I always carry fluids to moisten my mouth. (Dry most of the time)

8 Eating

- I enjoy eating out and have no problems
- I eat out whenever possible, but order foods that are not messy to eat
- I eat only with certain persons at selected places
- I eat only at home and only with certain people
- I always prefer to eat alone

9 Speech

- I am able to speak so that I am easily understood
- I am able to speak, but cannot sing or use inflection when I talk
- I am only able to speak clearly for short periods of time
- I am unable to speak clearly
- I do not speak

10 Breathing

- I do not have problems breathing
- I only have problems breathing when I have a cold or the flu
- I often have mucus build-up in my airway
- I seldom breathe as easily as I want
- I stay at home because of my breathing problems

11 Appearance

- My appearance has not changed very much
- My appearance has changed somewhat, but is not problematic
- I am somewhat concerned about my appearance
- I am uncomfortable with the changes in my appearance
- I do not participate outside of my home because of my appearance

12 Pain(1)

- I rarely have pain
- I have pain sometimes
- I have pain several times a week
- I am usually in some degree of pain
- I am in some degree of pain almost constantly

13 Pain(2)

- When I do have pain, it is very mild
- When I do have pain, it is mildly distressing
- When I do have pain it is intense
- The pain I have is very intense
- The pain I have is unbearable

14 Fatigue

- I seldom feel tired or fatigued
- There are periods when I am somewhat tired or fatigued
- I am usually very tired and fatigued
- Most of the time I feel exhausted

15 Please check the box next to the statement that best expresses the quality of your life during the last WEEK

- extremely unsatisfactory
- unsatisfactory
- moderately unsatisfactory
- the last week has been only slightly unsatisfactory
- satsifactory

16 Please add any concerns related to your disease or treatment that have not been asked about in this questionnaire

One of the most striking things about this description is the role of social factors in maintaining the problem. Thus, disfigurement is a problem because of the reaction of other people: going out is embarrassing – people stare and comment etc. Communication difficulties are, by definition, a problem in terms of their social function, but it is interesting to note that eating difficulties too have a strong social component – eating is a problem because it is embarrassing to drool or to use a child's cup. Understanding these difficulties in terms of social embarrassment allows us to design a rehabilitation programme which uses techniques of coping skills and graded exposure which have been successfully employed in the management of other kinds of social phobia.

2.iv What predicts good outcome for these patients?

- **Severity of dysfunction/disfigurement**

  One of the clearest indicators of good outcome is the extent of dysfunction and disfigurement. Dropkin et al (1983) developed a scale that allowed them to reliably measure the extent of disfigurement/dysfunction and showed that the more severe functional and structural loss was associated with slower recovery, prolonged social isolation, lower self-esteem and more severe depression. This is in contrast to the research on facial disfigurement across conditions which suggests no relationship between severity of disfigurement and distress. Patients with minor disfigurements are as likely to experience problems as those with a severe condition.

  The cautious advice seems to be that many other factors are important, and that whilst the severely impaired patient may logically seem the one for whom rehabilitation seems a priority, all patients should have the opportunity to take up the offer of support, counselling or skills training.

- **Social support**

  Social support has been clearly identified as important (see Section 3 for a fuller review).

- **Coping strategies**

  The question of adjustment and subsequent coping – with any kind of traumatic change in health functioning, appearance or social situation – is an issue which has long concerned researchers in psychology.

  In terms of disfigurement, research has demonstrated that patients use a number of different coping strategies, some avoidant, some specifically problem-orientated to overcome perceived difficulties. No identifiable 'best coping strategy' has been determined, but the most successful seem to be those who have developed a larger number and variety of strategies for dealing with problem situations. (Rumsey et al 1997)

  Dropkin 1992 has looked at coping in head and neck cancer patients specifically, and suggests that self care and social affiliation were the earliest manifestations of positive coping behaviour during the early post-operative period. Days 4–6 were considered vital stages in the acceptance of the deficit. Dropkin suggests that this is the stage at which the individual is well enough to manage personal hygiene and should be encouraged to do so, but that also the contact with medical staff and the beginnings of socialisation on the ward represent gradual exposure to social situations. She suggests that review on day 7 allows assessment of how well the patient is managing these two tasks, and that extra nursing input at this stage to establish these primary coping skills, can help to promote long-term coping.

  In terms of teaching coping skills, Fiegenbaum et al (1971) report a positive outcome with a small sample of patients recovering from head and neck cancer. Their programme consisted of client generated problem situations covering not only disfigurement-related issues, but also problems with speech and eating difficulties. Training in effective coping strategies led to significant reduction in social anxiety, and improvement in social skill. Despite the fact that this is a small sample, it is important in that it is the earliest study to suggest that skills training is effective, and this, together with the evidence from the study done by *Changing Faces* on a group of patients with a variety of disfiguring conditions including facial cancer (Robinson et al 1996), provides the basis for the development of the SRT programme.

2.v What do patients and their relatives want?

One of the best outlines of patients needs is the recent study by Dympna Edwards, published by *The King's Fund*. Her study was based on focus groups at different hospital sites, but produced some consistent findings.

- **Quality of life** was extremely important to patients and they stressed that head and neck cancer has a major impact on both patients and their families.

- **Information** was perceived to be either lacking or inadequate.
- Some of the most striking findings were concerned with deceptively simple issues, such as kindness and patience from medical staff, and someone available to really listen to their concerns, and advise. This suggests that **counselling** might have a role, and many of the patients in Edwards' study were aware that counselling has become an important part of rehabilitation after conditions such as breast cancer. Many people wished that it had been offered and felt that they were unable to ask unless it was offered. Some felt that counsellors would not understand unless they had undergone a similar experience. Listening rather than providing solutions was considered important.

- **Long-term support** from an informed professional has been highlighted as important in other studies. Parsons 1997 reported that patients often discovered that they knew more about the management of a tracheostomy or other aspect of their condition than their GP or district nurse. The opportunity to access very practical help. such as how to get hold of portable suction equipment was not available. Feber 1997 has shown that facilitating the skills of health professionals in the community by providing training for district nurses and inviting them to meet patients before discharge can considerably facilitate rehabilitation.

2.vi Putting it all together; what are the goals of rehabilitation?

In summary, we can see that patients undergoing surgery for head and neck cancer commonly experience long-term changes in their quality of life. Dysfunction and disfigurement lead to psychosocial problems and an increased psychiatric morbidity in the group as a whole. Those who do best appear to be those with good social support, and who develop effective coping skills.

In rehabilitating this group, we should therefore be aiming at facilitating both social support and the ability to manage the problems that the group encounter, whilst being aware that this needs to be delivered in a way that people find empowering, relevant and non-threatening.

Rehabilitation begins before surgery. Adequate information will be needed for effective decision making. Since people have differing information requirements, it can be helpful to provide a summary of what written information is available so that

people can choose what they want to know and when they want to know it. Where specialised equipment will be needed at home, it is helpful to provide and demonstrate this before surgery rather than afterwards.
Early involvement in self care, managing dressings, socialisation on the ward, all contribute to an ethos of self-management and independence which are the precursors to effective long-term coping.

In the same way, effective management of psychosocial issues begins early. *Changing Faces* suggests that all patients should be introduced to the idea of how to answer questions about physical appearance before discharge home. The aim here is to avoid the pattern of social avoidance which follows the fear of intrusive questions, comments and staring. Learning a simple answer to the question: 'what happened to your face?' and rehearsing it, for example whilst nurses and patients are involved together in dressings or similar procedures, can prepare someone to cope positively with an incident which often causes surprise and considerable distress.

If possible, the idea that new skills are needed for managing psychosocial issues is best presented in the context of the need to acquire new skills for managing physical change – such as managing a tracheostomy, a facial prosthesis, camouflage make-up, dietary needs etc. A firm emphasis on the substance or content of the programme (learning new skills) rather than on the process (meeting as a group) helps to facilitate participation.

Perhaps the biggest caution in implementing skills training is that **it does not replace the need to listen**. All sessions, whether group or individual, need to include some space in which the patient sets the agenda and in which there are not necessarily any easy answers. However, non-directive counselling alone, or support groups which are not well facilitated can be equally frustrating.

Finally, it is important to monitor progress. This is a new direction for rehabilitation and it is important to see how well it works. Not everyone will want to participate and not everyone will benefit. However, the evaluation forms included in this pack (Part Four) will provide a means of finding out whether or not this approach is helpful and for whom.

Section 3 – Social support and support groups

3.i Social support

Having a good quality social support network is increasingly identified as an important predictor of adjustment to illness. In her study of head and neck cancer survivors, Baker 1992 found perceived social support positively influenced patients' rehabilitation outcome six months post treatment.

But what is social support? Cobb 1976, defines it as: 'information leading a person to believe that he is cared for and loved, esteemed and a member of a network of moral obligations.' This is a start, but clearly, two patients might describe themselves as having equally good social support, one because he has a loving family in Australia, and the other because he has the practical day-to-day support of a helpful neighbour. In practice therefore, they would be talking about very different things.

Since this a term which means different things to different people, it is not surprising that the way in which it works is not fully understood.

Cobb suggests that social support facilitates coping with crisis and adaptation to change (which a person with any kind of disfigurement or dysfunction will inevitably have to face.) The paradox for patients with facial disfigurements, is that whilst social support is likely to be enormously beneficial, they are a group who are at risk of social isolation. Avoidance of others is a very common coping strategy because of the feelings of self consciousness and embarrassment in public places, together with feared responses from others of staring, comments etc. Not surprisingly, many people who are visually distinctive tend to spend little time with others outside the immediate family. This of course puts an added burden on the family who become the main providers of social support despite the fact that they may feel emotionally overwhelmed.

3.ii Patient-led support

One striking indicator of the need for long-term support has been the rapid growth of organisations such as *Changing Faces*, which have been founded in response to a need which the health service has been slow to meet.

Very little has been written about the role of support groups, but what there is, together with our experience suggests that the following are the three most common reasons for seeking contact with a support group:

- **Information**

  Good quality accessible information has become almost the universal hallmark of the effective patient support group. Whilst the best and most relevant information will always be that provided by the medical expert, accessing this has been a problem historically. Blaming the medical profession for being unwilling to provide time for patients, for using jargon and for withholding information 'in the patients interest' have been discussed at length, but patients themselves often feel that their questions are inappropriate. A focus on the role of the surgeon for example in terms of technical skill, can make people unwilling to ask questions which relate to quality of life and they may therefore miss the chance to talk to the person who is the best informed about their condition. Another problem is that in the absence of basic knowledge, it is very difficult to frame or plan relevant questions.

  A further issue which has received extensive study is the extent to which information delivered verbally can be understood and recalled.

  Patient-led groups have been quick to identify this gap, in particular encouraging patients to be assertive about acquiring information, and providing written information which will enable them to plan a successful consultation. *(See Changing Faces booklet 'Talking to Health Professionals about Disfigurement'.)*

- **Sharing the experience**

  Meeting other people who have had a similar experience has a major impact. This applies equally to relatives and carers as to patients. Many people stress their relief in knowing that they are not the only ones who have experienced the illness, and also that they are not alone in experiencing the tremendous range of emotions that go with the diagnosis and treatment. There are also many practical benefits in the exchange of information about coping techniques, what equipment might be available, access to specialist resources etc., especially where there is no Outreach service and where rehabilitation is left more or less up to the individual.

  A commonly expressed belief is one that 'you cannot understand unless you have been through it yourself', and meeting other patients and their relatives can sometimes be the only way in which this belief can be successfully challenged. Written information and video is also a useful tool, and people highlight case histories and examples as particularly helpful.

The drawback to sharing the experience is a major one, and the reason that some support groups fail. Where the experience has been a very negative one, where patients have post-operative complications, fail to make progress or die, then clearly support groups are having the opposite effect to the end intended. In combating this, some patient led groups have stressed the importance of having a trained facilitator who can ensure that sessions do not degenerate into a negative experience, or moaning session.

- **Advice giving**

  A third common role of a support group is the provision of advice. At *Changing Faces*, we see advice giving, not as telling people what to do, but as helping them to structure the process of problem-solving. One important function that has grown out of this approach is the process of working out alternative strategies for coping with problem situations, in particular social situations.

  Developing this approach in a group setting gives a quite different focus to a support group. The opportunity to meet others and share experiences takes place in a forum which is positive and geared towards understanding problems, so that individuals can develop coping skills and generate new coping strategies. Individuals are encouraged to experiment with different strategies and to report back progress. This skills-based support gives a momentum to long-term support, involves relatives by giving a constructive and clearly defined role, and allows patients to feel that they are making progress.

  (Part Two of this programme describes the way in which this can be achieved.)

3.iii Setting up a support group

Not everybody wants to take up the offer of support. One of the major frustrations of carrying out this work is the fact that the people who would most benefit are the least likely to take it up. One obvious reason is that by definition a group involves social interaction, and this is precisely the nature of the difficulty for this patient group. However, this is the case for all social skills groups, and one way that helps to 'sell' the idea is to describe the group in terms of a specific agenda. The opportunity to talk about their experience in terms of feelings and emotions is a major turn off for a large group of people. The opportunity to learn about how to manage some of the more challenging aspects of rehabilitation is more appealing, and the fact that relatives are included in the programme is also helpful.

- **Who will benefit?**

  Changing Faces recommends that all patients are offered the chance to participate in this programme. We have argued elsewhere that discriminating between groups on the basis of type or severity of disfigurement has no foundation. Everyone who looks unusual is likely to experience staring or comments, and facial cancer patients often have the added stigma of speech and eating difficulties. The fact that this approach is offered routinely has the added advantage of reducing the stigma associated with being picked out as particularly vulnerable.

  Some people will not want to participate. For them, there may be the opportunity to work on a one-to-one basis. (The graded exercises in Part Three can be used in group or individual settings.) If not, then the relevant booklets in the pack have been produced in a self-help format. These can be offered as a minimum intervention.

- **Where should groups meet?**

  There often is little choice about this. Whilst there is some argument that meeting away from the hospital is part of becoming independent of it, patients often want to keep the link with their medical team open. Meeting back at the hospital can be very reassuring, and keeping the contact with the head and neck nurse over the few weeks necessary to run the programme is a useful way of providing this link in the early days back at home.

- **How often should groups meet?**

  The programme is set out to run on consecutive weeks. This is one model, but where it is not possible, the units in the manual can be combined or used to generate a problem-focused session.

  ◊ For example, a group that meets every three months might take a particular topic for discussion (e.g: eating in public) and use the materials to support it.

- **Who should run groups?**

  This manual is written for head and neck nurses, many of whom are running support groups already. They are the ideal facilitators.

  Where nurses have not run groups before, it may be possible to set up sessions with the support of a clinical psychologist. *Changing Faces* will also run training days for nurses in how to use these resources.

3.iv Exchanging information

In some parts of the country, it is not possible to run a rehabilitation programme because services are not centred in one place, or because patients live too far away to undertake the travel.

Keeping a database of patients who are willing to talk to others either on the phone or in person provides a means of linking people who would otherwise be isolated. Volunteers are often very keen to be involved in this kind of 'exchanger system'.

An alternative is to set up an interactive newsletter. This could include contributions from patients, but could also use materials from the pack to introduce management strategies for specific situations, e.g: speaking on the telephone.

Finally, a telephone number where people can access further information or speak to someone if they have a problem is invaluable. It does not have to be available all the time as long as people know the times when it will be manned.

Advice on running support groups can be obtained from other charitable organisations. These include *CancerLink* and *Contact A Family.* There is also an excellent introductory guide: *Self Help Groups, Getting started, keeping going.* by Judy Wilson and Jan Myers, which is designed for patients setting up groups but has some useful practical advice (see addresses and references at the end of the pack).

Section 4 – Skills: training and methods

4.i What are social skills?

In every social interaction, success depends on our ability to communicate clearly with the other person. We need to demonstrate our awareness of the other persons needs and express our own clearly and effectively. Our ability to do this has been described as social skill.

Other definitions of social skill are given in terms of the behaviours that we use to achieve communication. Often broken down into verbal and non verbal skills, these range from tone of voice and verbal fluency to conversation skills, posture, hand gesture, eye contact, etc.

Essentially, social skills are those overt behaviours which support interaction with other people.

4.ii Background and explanations

Interest in the value of social skill to the well-being of the individual has its roots in the early 1960s, with evidence that poor social skill was associated with the perpetuation of psychiatric disorder such as depression. Since that time there has been enormous interest in the effectiveness of social skills training in a range of conditions including psychiatric disorder, learning disability, and conditions which result in the individual appearing visually or behaviourally unusual, such as facial disfigurement and cerebral palsy. In very simple terms, for those people who appear to be different and whose presence can create uncertainty in the general population, social skills training has aimed to teach skills that reduce the sense of isolation and loneliness and allow them to fit in.

More recent studies demonstrate that social skills are most effective where training has a problem-solving focus, and this is the kind of programme that *Changing Faces* has developed for use with people who are visually different. Clients attending workshops learn to develop basic skills like eye contact, posture, and how to develop their language and conversation skills. They employ these skills in developing strategies to manage the problems of visible difference, and they then practise using these skills in specifically targeted situations.

◊ For example: staring is a commonly reported problem by the disfigured population. Good posture and firm eye contact together with an assertive statement are strategies which can be rehearsed and then practised in settings where the individual feels vulnerable, such as on public transport.

4.iii Head and neck cancer patients

For this population, facial appearance is only one of a number concerns which commonly include difficulty with eating and speaking. Anything that reduces anonymity can lead to social anxiety, and many people express their concerns in terms of self-consciousness and embarrassment. The common tendency to withdraw from or avoid social interaction, is a feature that this population shares with others which feel stigmatised.

In extending the *Changing Faces* approach to this population, problem-solving skills target not only the self-consciousness and embarrassment surrounding issues of appearance, but those surrounding the difficulty of executing everyday behaviours. Breaking down a task into its simplest form, planning a strategy for managing it and then testing it can equally be applied to problems like eating in public.

4.iv Can these skills be learned?

Social skills are normally learned during social development, but like any learned behaviour, they can be taught.

Training employs some basic principles which are built into the programmes in Section 2. Learning a new skill relies on the **transfer of information** from one person to another.

- **Modelling**

  This can be done verbally or in written form, but commonly in social skills training by behavioural modelling, in which a skill is demonstrated. For example, the importance of eye contact can be described and illustrated in a simple practice exercise. Modelling how intrusive questions can be answered or how to ask for food to be prepared in a specific way is a good starting point for patients to develop their own ideas and to become familiar with and relaxed about the task before they try it themselves.

In modelling any kind of behaviour, it is important to acknowledge some task difficulty, and to model coping effectively rather than brilliantly! Making the task look too easy can promote feelings of inadequacy if difficulties arise in carrying it out.

- **Behavioural rehearsal/role play**

  Role play or behavioural rehearsal, involves the patient in practising the behaviour themselves. During this stage, **feedback** from the facilitator is used to encourage and develop those aspects of behaviour that were effective, and to identify those aspects which need further work. Praise and encouragement are vital. All members of the group can offer feedback, and modelling how to give feedback in a positive and helpful way is an important aspect of involving patients' partners and teaching them how they can offer constructive support.

- **Independent practice**

  Independent practice of the target behaviour is carried out by the patient himself, who records progress for discussion at the next session. Frequent repetition of the task is more effective than trying it out intermittently. Tasks such as buying a daily paper which can be done every day are good basic exercises.

4.v Creating a positive experience

A social skills training group is a therapeutic group, and it should not be experienced as demoralising. Support groups are often set up by patients as a means of identifying others in a similar situation, but they can become a negative experience if the focus is on describing problems rather than managing problems.

All groups should include a 'socialising component', and it is useful to spend the first ten minutes of a session in general discussion.

Warm up exercises consist of simple techniques of ensuring that everyone feels comfortable in the group and is playing a part in it. Getting used to speaking in front of others can be hard, especially if speech is affected. Selecting exercises which are light-hearted, such as describing the front room, or a favourite holiday destination create a non-threatening environment, as well as practice of simple conversation skills.

4.vi Structure of sessions

In the first sessions of the programme, the emphasis is on developing verbal and non-verbal communication skills. These are then used to focus on the specific communication problems for this population, and generate some problem-solving strategies.

Problems of appearance, eating and speech are specifically targeted.

Modelling and role play are used throughout the sessions to develop a repertoire of skills, with the patient and his/her partner working together as far as possible to develop a working support unit which continues to operate outside the group.

'Putting it into practice' consists of target situations which the patient pair work at together. These consist of everyday situations for which the pair must generate a management solution. A hand-out for each situation allows them to do this by considering the problem under the headings:

⇒ TASK

⇒ TOOLS

⇒ TROUBLESHOOT

⇒ TEST

Having generated a solution, the task is practised and the outcome recorded in diary form.

Outcome is discussed at the next session.

PART TWO: PUTTING IT INTO PRACTICE

How to use this six-session guide

This session guide has been produced in the form of a manual. Detailed instructions for running six sessions are given.

The six sessions start with a general introduction to social skills, before teaching the specific tools and strategies which are useful for this group in managing the effects of altered appearance. These strategies are also applied to alteration in speech and eating difficulties.

Although each session is laid out with verbatim instructions to be given to the group, these are intended as examples only; it is assumed that the trainer will convey the content in his/her own words. This device has been used simply for completeness. To help the trainer in the practical running of the sessions, the following layout conventions are used. However, it is important to stress that they are intended to be helpful and not prescriptive.

"..."	Bold quotes indicate a suggested form of words for the trainer.
"..."	Single qotes indicate example quotes from patients, onlookers etc.
italics	Italics indicate instructions for the trainer.

- **Should I work through each session in order?**

  You may not need to include all of this material and examples with your group. If you have a group who have very good social skills, then a brief summary will be enough. However, these early sessions are deliberately light-hearted, and can be an important way of introducing role play and discussion before moving on to the specific problem-focused strategies.

  Similarly, you may want to give more than one session to a topic such as REACH OUT.

- **How big should a group be?**

  These exercises are aimed at a group of about four to six couples. Many relatives feel that they are asked to provide support without knowing how, so ideally, partners, i.e. a relative or a friend, should be included as members of the group. This gives them the opportunity to learn some of the problem-focused strategies, and also to become accustomed to the routine discussion of issues with their partner and forward planning of difficult social situations. They also have the opportunity to meet other carers and supporters in a constructive environment.

Alternatively, patients may choose to attend the group alone, and they can then either partner each other or the trainer for the exercises.

- **What if I don't have the resources to run a group, or no-one wants to attend one?**

  This is not a problem. You can work with people either individually or with their partner using these materials.

  - ◊ For example: you might use a session to talk about the importance of non verbal communication with a patient who has had a laryngectomy, using example exercises from the sessions on communication skills.
  - ◊ For example: you might use a session to outline the SCARED model to someone who is particularly concerned about other people's reactions.
  - ◊ For example: you might focus on a specific problem or event such as staring, or an unpleasant comment, in which case the booklet *'Everybody's staring at me'* can form the focus of a session.

- **Using the additional resources**

  Booklets and video are included in the pack. These support the exercises in the group and provide a basis for discussion within the group. They are often used to support a homework task with a view to extending the work done into the home environment. They can be used in a one to one setting as well as in a group, or given to people who cannot attend regular sessions.

  You could also use information and examples from the booklets to inform a regular section in a newsletter, if this is a strategy for support that you think your patients would find helpful.

- **Be flexible!**

  Focus on the patient who has the condition, rather than the condition that the patient has. Modify these resources to suit both them and you.

Session 1 – Introductory Session

Introductory session includes:

⇒ purpose of the sessions
⇒ getting to know other members of the group
⇒ hearing other people's concerns: patient – carer
⇒ introduction to SCARED
⇒ introduction to homework tasks

1.i Aim of the sessions

This first session is a general getting to know each other session, and introduction to the aims of the course. The following explanation can be used:

" People who have had surgery to the head and neck often say that they have been very well looked after in hospital, but they wish that they had more support when they got home. Relatives often say that they really want to help but don't know enough about what the problems are or how they can help. They also say that it is very helpful to meet other people who have undergone the same kind of surgery, to find out how they are coping and any practical tips and suggestions that they have.

This group is about meeting other people in a similar situation, sharing some of the problems but especially, finding out what works for other people.

We shall be doing lots of talking, watching some video from time to time, and there will be information to take home to think about. Sometimes I shall be suggesting some ideas that you might like to try out at home. The idea is that this is a support group – but one which really tries to build up your confidence about the future.

Rules of the sessions: We need to have some simple rules to ensure that everyone feels comfortable. These are simple things like giving everyone else the chance to speak, and keeping what is said within the group confidential."

1.ii Personal stories

Each person (including relatives) gives a ***brief*** *account of their story. Instructor models this with a brief description of his/her story. Some disclosure is important here; e.g: whether married, children, interest in this work etc. Watchpoint: this is not intended as a long autobiographical session, but as a means of disclosing enough about each person for everyone to feel a common sense of purpose. Instructor uses prompt and reflection to summarise each story and gives feedback. (Thank you).*

1.iii Hearing other people's concerns

This exercise is intended to open up discussion about the things that most immediately concern the group. Using a flip chart, divide down the middle into two columns, one each for relative and patient. Try to elicit at least one concern from each person. Prompting can be used to get the group started. Try to assemble problems under general headings as follows:

PATIENTS		CARERS
"I'm worried about whether my surgery has been successful"	**diagnosis of cancer**	"I'm worried about whether his/her surgery has been successful"
"I'm worried that people will stare and ask questions"	**altered appearance**	"I'm worried about people staring and asking questions"
"I can't face going out"		"I don't know whether I should do things for him/her or suggest that we go out together"
"I don't know what to say if people ask me what happened to me"		"I don't know what s/he would like me to say to other people"
"I'm worried that I'm no longer attractive"		"I think s/he's worried about being attractive and I don't know how to reassure her/him"

"I'm worried people can't understand what I'm saying"	**speech difficulties**	"I don't know whether to answer for him/her"
"I can't eat properly"	**eating difficulties**	"I don't know how to help with food"
"I feel embarrassed eating in front of others"		"How can I help when we eat out"

Try to elicit as many issues as possible, using questions:

◊ *"Is this an issue for anyone else?"*

◊ *"I noticed you nodding as x was speaking, is this something that concerns you too?"*

Don't labour the point. The aim is not to produce an exhaustive list, but to demonstrate that:

⇒ people have the same issues and concerns

⇒ relatives share these concerns

⇒ many of these problems can be resolved by talking about them, e.g:

"should I answer for my husband?"

"what does she want me to say?"

<u>Summarise</u> *the points above, recording them on the flip chart.*

[<u>Other peoples' stories</u> Video clips can be inserted here, particularly if the group seems hesitant about speaking freely, and to emphasise the focus on coping. If the group is well engaged, move straight on to SCARED]

1.iv Introduction to SCARED

Use the explanation below to introduce the exercise:

" This is an exercise aimed at exploring the normal reactions and emotions experienced when first meeting someone who has an unusual appearance, particularly when this follows surgery for cancer. Many of the concerns listed on the flip chart relate to what other people are going to think or do.

- ◊ Are they going to stare?
- ◊ What will they say?

When you first meet someone who has had major surgery of this kind, you may not know where to look or how to react to them. You may feel embarrassed or just generally awkward. The person involved may also feel similar emotions, as well as feeling defensive and unsure of themselves. This can create a big chasm which can lead to a negative meeting that is upsetting for both parties.

This is called the SCARED syndrome. This SCARED exercise helps both the individual and the person who meets them to examine their own reactions, and accept that these may be normal."

Overhead 1 shows a chart using SCARED as an acronym.

CHANGING *faces*

OVERHEAD 1

SCARED SYNDROME

After head and neck surgery, a person may:	**Someone who meets this person may:**
S be *S*elf-conscious or *S*hy	S *S*tare, be *S*ympathetic/*S*hocked
C feel *C*onspicuous	C be *C*urious
A feel *A*lone, *A*ngry, *A*nxious	A *A*ssume, feel *A*nxious
R feel *R*ejected	R *R*ecoil, feel *R*epelled
E feel *E*mbarrassed	E feel *E*mbarrassed, want to *E*vade
D feel *D*ifferent of *D*epressed	D *D*read it or feel *D*istressed

Draw up the chart on a flip chart omitting the reactions against the letters:

After head and neck surgery, a person may:	**Someone who meets this person may:**
S	**S**
C	**C**
A	**A**
R	**R**
E	**E**
D	**D**

Invite the group to give you examples of reactions that fit against the letters, starting first with what they think that they might feel, and then what someone meeting them might feel. Discuss these reactions and emotions as they are given.

Ask the group if they have experienced any of the reactions and feelings described and to describe the situations in which these feelings emerged.

1.v Turning things around

The following explanation can be used to explain what can be done to manage the SCARED SYNDROME.

Insert SCARED SYNDROME Overhead 1.

" Once we have an idea about why things go wrong, we can start to think about how we can manage situations in a way that helps them to go right.

We know from our own experience that getting things right in the first few minutes can shape the whole way in which an encounter develops.

We also know from research that taking the initiative in social situations is the means to getting things right! Getting in first before people make faulty judgements.

This is what these sessions are going to be about. We are going to learn all about communication, including some new ideas and strategies, so that we know how to intervene before the SCARED process has a chance to develop.

We shall cover all sorts of different challenges, all of them concerned with managing social situations from joining in a conversation to managing a meal in a restaurant."

1.vi Introduction to homework tasks

Explain that the next session will focus on communication, understanding the role of the face and how to communicate when the face looks different.

Ask each couple to take a copy of the booklet 'When cancer affects the way you look' and read it before the following session.

Explain that each week, a simple task like this will be given to reinforce the work that has gone on in the group.

Each couple should try completing the table on page 17.

Thank everyone for coming, and stress importance of attending regularly.

Session 2 – Non-verbal communication skills

Resources: 'Everyone's staring at me' booklet.

This session includes:

⇒ eye contact
⇒ posture
⇒ body language
⇒ handshake
⇒ smile

2.i Recap on last session and outline of today

" Last week we had our first meeting and introduced ourselves to each other. We looked at some of the difficulties that we share, and you took home a booklet to read and fill in the table on page 17."

Collect feedback about the booklet. What was useful? How many of the weekly activities they listed in the table are influenced by appearance?

"We then we went on to think about how other people might feel about us, how they might be SCARED of doing the wrong thing, and how easy it is for communication to break down.

This is not as depressing as it sounds, because we know that there is lots that can be done to stop people being SCARED. What we have to learn to do is to communicate well, to get our personality across before people can make faulty judgements about us. And research shows that if we can do this, people pay attention to who we are, and not to what our faces look like. In the next two sessions, we are going to try to understand more about communication, and to get some feedback from other people in the group about how we present ourselves."

2.ii Eye contact

- **Warm-up exercise**

  Introduce the idea of warm-up exercises as a means of breaking the ice and getting everyone used to speaking in front of the other group members.

  " I would like everyone introduce themselves, and tell the group one good thing that happened to them in the last week."

◊ *Trainer begins:* "Hello I am x.... Last week, I spoke to a very old friend of mine on the telephone and caught up with about two years worth of gossip. It was really nice to talk to her."

After each contribution, trainer thanks each person and comments on their contribution.

At the end of the exercise, trainer points out how communication depends on the face.

" We all look at people both when we are talking and when we are listening. Our faces are the central focus when we are communicating with other people. The part of the face that we focus on the most are the eyes."

Depending on the nature of facial disfigurement in the group, it may be appropriate to point out the facial triangle and that disfigurement outside this triangle such as facial palsy, may be less disruptive to communication than other injuries.

" The average eye contact lasts about three seconds, and it is very hard to communicate without it."

- **Speaking, without eye contact**

  Trainer gives the following instruction:

  " I would like each person to turn to the person on their right, and briefly describe where they live. In doing this, I would like you to avoid eye contact, by looking at the floor instead of the other person."

  Try to elicit the way this made people feel. List on flip chart. Try to include:

  - ◊ *made me feel uncomfortable*
  - ◊ *person came across as not interested*
  - ◊ *made me feel as if they were avoiding looking at me*
  - ◊ *made me want to get away*
  - ◊ *very boring*

  Discuss the way that looking directly at someone else implies interest and conveys more information.

  " This is important when we are speaking, but also when listening."

- **Listening, without eye contact**

  Trainer gives the following instruction:

  " Now I would like each person to turn to the person on their left, and describe the colour of their living room. You can look at the other person, but the listener has got to look at the floor."

  Refer to flip chart. Try to elicit any more feelings.

  " If you don't look at people when they talk to you, you give the impression that you are bored and uninterested. They will quickly find someone else to speak to. Even though you may feel self-conscious about your face after surgery, you will communicate with people much more effectively if you look at them directly. If eye contact is difficult, try looking just above the eyes at a point above the nose; this feels the same for the person with whom you are speaking."

  Get each couple to try this out on each other.

2.iii Posture

(NB: these exercises may not be relevant for patients with reduced shoulder mobility.)

- **Posture exercise (i)**

  Ask the group what they noticed about the way in which they were sitting when they were avoiding looking at people. Try to elicit the change in posture, slumped shoulders etc.

  <u>Model</u> the way that they came across by describing your front room to person sitting next to you. Exaggerate the slump in shoulders. Model how shoulders go back and posture erect when looking at people. Stress how this alters the message being given.

- **Posture exercise (ii)**

  Ask everyone to stand up and to think of a circumstance when they felt very confident and pleased with themselves.

  Everyone now has to think of a time when something went badly and they felt awful about something, e.g: forgot to do something important, scraped the car, burnt the supper. (Reassure that they don't have to say what it is!)

Try to encourage people to really recapture the way that they felt. Point out the change in posture as they think about the bad thing – shoulders slouched, face down etc.

Now ask everyone to stand up straight, shoulders back but relaxed. Arms freely by side, looking straight ahead. Walk amongst group correcting posture where necessary.

Now ask everyone to think of the bad thing again, but without altering the way that they are standing. Elicit their experience. It is very hard to feel self-conscious and embarrassed whilst standing confidently.

◊ Summarise by stressing the impact of how we feel on our posture:

> " You can see by doing this exercise that by making an effort to stand tall with good posture, you find it harder to feel self-conscious and embarrassed. You can actually begin to convince yourself that you feel positive and confident, and that is how you will appear to other people."

Model a good confident walk. Keep head up, shoulders back, arms at side and smile exchanging eye contact with the group. Repeat, walking around the group and shaking hands with each. Ask for volunteers to try walking into the group, as if they were walking into a room full of people. Encourage relatives to do this first, but don't put pressure on people to do it.

As people take turns to do this, stress the positive aspects of what they are doing before gently pointing out what they can change. Stress the face, and the importance of eye contact. Encourage the group to offer feedback to the others and to practise at home.

2.iv Handshake

Model walking into the group and shaking hands with each in turn.

Elicit comments on handshake. What messages does it give other people? Ask each couple to shake hands with each other and give feedback.

◊ Summarise: A good firm handshake gives lots of information about feeling confident. A weak or limp handshake conveys the opposite. Here is something that you can practise which has nothing to do with your face, but which will influence the way people respond to you.

2.v Body language

" I would like everyone to turn to their partner, and for one of the pair to briefly give directions for how to get to the nearest station from their house." NB: speaker need not necessarily be the patient.

Elicit feedback from the listener.

" Was the person looking at you? Apart from the message, what else did they do? What did they do with their hands? How did this help to get the message across? "

Swap over. Now the other partner describes how to get to their nearest supermarket, but sitting on their hands.

Elicit feedback from both partners.

" Was it harder to do without gesturing? Did it seem strange to listen to? "

◊ Summarise:

" Where we can't use our face to help us communicate, we tend to use more of our non-verbal communication skills. On the telephone, we ummm and aha much more than in direct conversation.

Using your body language to communicate is an important tool where facial expression, like smiling, is harder. So to show that I am listening to someone, I first look at them. I can nod my head to show that I am attending. I can smile. What if I can't smile? Then it is more important that I keep the eye contact steady, I might nod my head more or I might touch people more."

Model gentle squeeze of the arm to say thank you.

- **Homework task**

Trainer gives the following instruction:
" I would like each of you to watch some television this week. Choose your favourite 'soap' and watch the first few minutes with the sound turned down. Look at the way in which people use non-verbal communication to reinforce the message. Look at how they use their eyes to make sure that they keep someone's attention."
Thank the group for coming, outline the focus of next week on verbal communication.

Session 3 – Verbal communication skills

Resources: 'Everyone's staring at me' booklet

This session includes:

⇒ tone of voice
⇒ initiating conversation
⇒ speech difficulties, laryngectomy

3.i Recap on last session and outline for today

" Last week, we thought about how faces are important in communicating, and then we went on to think about all the non-verbal aspects of communication. We did some exercises looking at eye contact and posture, gesture etc. and then you all went home to watch some television and see how people use non-verbal skills."

Elicit feedback: could they decide how people were feeling from the gestures they were using. Did anyone watch anyone who was angry? Sad? Happy? Etc. Which characters in the soaps make the best use of gesture? Facial expression?

" This week, we are going to think about verbal communication. This will include all kinds of information that you give to people by the way in which you say things – how quickly you say them, your tone of voice, whether you speak loudly or softly, all the ers and ahs etc. and so on. Some of you have experienced changes with your speech, and we will be particularly interested in how this affects the way you communicate with other people and how you can do this most effectively."

3.ii Tone of voice

" I want to go around the group, and for each person to tell us the best present or one of the best presents that they have ever had, and why it was so good."

◊ Trainer starts: "The best present I ever had was.................................."

The aim is to choose something light-hearted, and to be really enthusiastic about it to demonstrate the effect of tone of voice, e.g. the gadget that helps get the lids off screw top jars.

Everyone briefly describes their present. Thank each person and comment.

Point out how everyone used inflection and varied speed of delivery in their description.

" Now I want you to do something similar. I want you all to tell everyone about the best holiday that you ever had, but I want you to do it in a very flat uninteresting way."

◊ Trainer starts: "The best holiday I ever had was........................."

" Now, working in pairs, can you do the same? I want one of you to tell the other about you best holiday, but in a flat voice."

Elicit feedback. What was the effect? Did it make them want to go there? Would it be interesting to sit next to this person, or have a longer conversation with them?

Watchpoint: *What happened to their body language as they spoke? Elicit the way in which the whole person tends to slump and the loss of eye contact. Flat tone tends to make the message quiet and mumbled.*

◊ Summary: " The message is more exciting if presented in an enthusiastic way. Good posture and eye contact will set the scene. Use a clear firm voice. Slower rather fast speech is clearer, varying the pitch and tone of voice is important, don't shout, but don't speak too quietly either."

3.iii Initiating conversation

" What do people say to each other? How do they start talking? Many people feel their mind go blank in social situations, especially trying to talk to someone they have only just met. It is all the harder if you feel self conscious or ill at ease. However, there are some very simple things that will make this easier."

Use flip chart. Try to elicit ideas, in particular:

⇒ What do you and the other person have in common?
  ◊ work
  ◊ children at same school
  ◊ live in same area
  ◊ friends of same people etc.
  ◊ at the same event - why?

⇒ Focus attention on the other person:
  ◊ clothes and jewellery
  ◊ holidays
  ◊ work

- **Keeping the conversation going**

  Show that you are interested and listening:

  - ◊ use your non-verbal skills – eye contact, nodding, etc.
  - ◊ use questions: Who? Where? When? What? How?
  - ◊ use statements about yourself
  - ◊ be prepared! What is happening in the news locally/nationally?

  Refer to the booklet 'Everybody's staring at me' for further examples, and give a copy to each couple in the group.

  Practice: Ask each couple to look at the examples on page 15 of the booklet. Each couple together work out answers to the two examples. Go around the group and elicit each answer in turn.

3.iv Specific speech difficulties

The following exercises are aimed to promote confidence for people who have speech difficulties. They can be omitted if not relevant to the group, or introduced later in the session on managing staring and comments.

" After surgery on the face, some people experience problems with their speech. These can include a tendency to slur your words or speak less distinctly. Where you have had an operation on your larynx, you need to work out how you are going to overcome the loss of your voice. Your speech therapist will help you to master these new skills, but it is also useful to think about the impact of sounding different, in the same way as we are thinking about the impact of looking different.

There are a number of different ways of communicating after laryngectomy, and most people use a combination of them. They include:

- ◊ electronic larynx
- ◊ voice prosthesis (valve)
- ◊ oesophageal voice
- ◊ silent articulation (mouthing words)
- ◊ pen and paper

One of the common things that people describe when their voice changes is the feeling of being different. For some, it can feel like a very big personal loss, as if part of your personality has been altered.

What are other people going to do if you sound different? What are they going to think? Our SCARED model can help us here."

Put up SCARED model (Overhead 1) on OHP.

" Remember, people are uncertain when meeting something that they have not met before. They can make assumptions. One fear that people have if their voice is slurred, is that people will think that they have been drinking. If your voice sounds different, then people may turn and look. Remember, most of them have never heard anyone use a servox and they may react by staring or questioning. They may well ask you "What happened to your voice?" They are simply curious, and anticipating their response makes it easier to manage."

Using flip chart, elicit things that are going to make communication easier, starting with non-verbal skills.

Non-verbal skills

- face the person directly, so that they can see your mouth for lip reading
- good eye contact
- stand up straight
- use gesture and expression
- smile

Having your answer ready (see examples overleaf)

- answering with the minimum of information
- answering and changing the subject
- answering with lots of detail
- introducing the subject first
- "Please listen carefully, I've had an operation on my face." (Very good strategy for phone calls)

DON'T APOLOGISE!

- **Homework task**

Trainer gives the following instruction.

" Last week you watched television to see how people used their non-verbal skills. This week, I would like you to watch the news or the weather forecast, and listen to the way in which the presenters exaggerate their voices to maintain your interest.

Could you also read the first section of the staring booklet – up to page 9, for more ideas about conversation skills."

Thank everyone for coming, and introduce the topic for next session – Tools and Strategies.

Answering questions about changes in voice

⇒ ***examples which give a minimum of information and close the subject:***

"I had an operation on my throat years ago, but it doesn't bother me now"

"I had an operation on my throat but most people understand me very well."

⇒ ***examples which answer the question and change the subject:***

"I had an operation on my throat. You're very brown, have you been on holiday?"

"I had an operation years ago; tell me, is this pub always this busy?"

⇒ ***examples which potentially open the topic for discussion:***

"I had throat cancer; it is becoming more common......."

"I use a servox. Have you ever seen one before? It has a vibrating membrane....... etc"

⇒ ***examples which use humour to break the ice:***

"At least people can always remember who they spoke to....."

"It's given a whole new dimension to swearing!"

Session 4 – Tools and strategies

Resources: *REACH OUT video*
Making the change

This session includes:

⇒ Using your communication skills
⇒ Recap on SCARED
⇒ Taking the initiative
⇒ Introduction to REACH OUT
⇒ Building a partnership, developing a personal code

4.i Recap on last session, debrief on homework and outline of today

" Last week we thought about communication skills, and in particular, how we use our voice when we are talking to people. We did some exercises to show how much more interesting things sound if you vary the tone of your voice, and we also thought about communicating when you have some difficulties with speech.

You all went home to listen to how people use their voices when they are giving a message. You were going to listen to the news and see how important verbal skills are in maintaining your attention, even when there is plenty to watch."

Elicit feedback. How do the newscasters use their voice? NB: exaggerated rise and fall, good pace of delivery etc. Are these ideas useful to them?

" You also read the section on conversation skills in the booklet."

Was it helpful? Which ideas were new? Have they tried using any of the ideas themselves?

4.ii Using your communication skills

- **Exercise 1: Warm-up exercise**

  " I want to go round the room, and each of you tell me who is your favourite news reader or weather girl, and why!"

  ◊ *Trainer starts:* "My favourite weather girl is..........................."

  The aim, as with all the warm-up exercises is to set the scene for a relaxed and enjoyable session, whilst encouraging everyone to participate.

  Go around the room in turn. Comment on and praise each contribution.

  " Now that we have done some basic work on communication, we are going to think about using these skills to help us manage everyday situations."

4.iii Taking the initiative – Recap on SCARED

Trainer shows overhead of SCARED.

General review and revision of the SCARED model picking up the following points:

◊ people are <u>uncertain</u> about things which are unfamiliar
◊ uncertainty leads to <u>*lack of skill*</u>
◊ lack of skill leads to <u>*avoidance*</u>
◊ avoidance is manifest as *avoiding eye contact*
not knowing what to say
saying the wrong thing
talking to your partner instead of you
avoiding you altogether, etc.

" Today, I want to think about how we can learn to manage situations in which people may be SCARED, by learning to take the initiative."

4.iv Introduction to REACH OUT

" To help you, we have a tool box, which we call REACH OUT, and I am going to show you a video which illustrates this."

Put up REACH OUT (Overhead 2) and explain.

OVERHEAD 2

REACH OUT

R	**REASSURANCE**
E	**EFFORT**
A	**ASSERTIVENESS**
C	**COURAGE**
H	**HUMOUR**
O	**OVER THERE!**
U	**UNDERSTANDING**
T	**TRY AGAIN**

- **Taking the initiative**

This is the golden rule for dealing with an unusual appearance. Your aim is to make the first move, and to impress your personality on other people before they have a chance to make a faulty judgement about you based on face values.

" We use the phrase REACH OUT to describe a set of skills, where each letter represents a strategy that you can try. Some people have good social skills and find that they are automatically using the skills described below. Other people find that they are better at some skills than others, and there are some that they need to practice. With time and practice, people find that they become so good at using these strategies that they enjoy the challenge of new social situations and new people rather than disliking or even dreading them."

R Reassurance

" You need to reassure people that they have no reason to feel uncertain. Eye contact is critical here. If you look away, you will come across as uncomfortable and ill at ease, and that is exactly how they will feel too. Hold your head up and look at them. Don't worry if they seem bothered about whether to look at you. They will relax as they begin to see that you feel comfortable and at ease. A smile will help you enormously, and if you can lead the way with a question or a general statement, this will help to send them the clear message that there is no need to behave any differently with you than they would with anyone else."

E Energy and effort

" It is very important to try to match the energy and effort of other people if you are going to appear interesting. Enthusiasm will help to make people attend to what it is that you are saying, and not what you look like. Your voice can help you too. The more expressive the tone, the more interesting you make the content. By making use of other communication skills, nodding your head, using your hands expressively, you will rely less on eye contact to convey the non verbal parts of the message."

A Assertiveness

" Think about your posture and the way you move. If for example you come into a room apologetically, head bowed, you make a very different statement from someone who comes in with their shoulders relaxed but upright. If you shake hands with someone, make sure that you have a good firm grasp and not a limp one, and look at them with a smile as you introduce yourself. Confidant eye contact is vital if you are to present yourself assertively. Lead the way; by looking directly at them, you are signalling that it is okay for them to do the same in return. A clear, firm voice will help to convey the image of someone who feels positive and confident, and people will respond to you in the same way."

C Courage

" This can be difficult to start with, especially if you feel that people are curious about you. Other people may appear to be the confident and capable ones, (although often, people may appear much more confident than they feel), but with each small success you will find that you feel more confident about tackling new situations."

H Humour

" This is one of the most effective ways of breaking any tension. It also gives you the chance to take the initiative in a light-hearted way. It tells the other person that you feel relaxed and at ease and that they can therefore feel the same way."

O Otherness, Over there

" This is one of the simplest and most effective strategies for shifting the focus of attention away from you to the other person. You can do it very easily by commenting on something that the other person is doing or wearing, or something that is happening elsewhere in the room. It works particularly well immediately after an introduction, so that before there is time for an awkward pause, or everyone starts looking at their feet, you have led the conversation the way you want it to go."

U Understanding

" When you are concerned with your own feelings, it can be difficult to recognise that other people may be feeling uncertain and unskilled. They may not know how to behave. Should they ask you about your operation or not? Will you be upset or offended? It is easy for them to take the easy option and avoid talking to you.

What you have to remember is that this uncertainty is not the same as hostility. It is not that they don't want to get to know you, but that they aren't sure how. You are the one who has the skills here. You are the one that can demonstrate by your own relaxed behaviour that there is no difference between getting to know you and getting to know anyone else.

You might find that it helps to mention your face in the conversation. This gives a very clear message that you are not embarrassed or concerned about it."

T Try again

" Don't get discouraged! There is no such thing as failure, only feedback. If you feel things did not go well, try to work out what this tells you for next time. Using REACH OUT is exactly like learning to ride a bicycle. You have to fall off a few times in order to learn what you are doing wrong."

Show *REACH OUT* video.

Debrief: Point out how *REACH OUT* makes use of the communication skills that have been learned in the previous sessions.

4.v Building a partnership and personal codes

In this section, the emphasis is on working together as a partnership with either a friend or family member supporting the first steps back into social situations.

" In the video, the young man was on his own in most of the situations we saw. I want to finish today by thinking how partners can help. Many social situations involve two people. How do you think that you can support your partner when you are together?"

Use flip chart to brainstorm ideas, e.g:

◊ hold arm or hand
◊ sit next to him/her
◊ explain to other people (e.g: which side to sit, what food to prepare)
◊ do the talking for him/her (is this what is wanted? What will you say?)
◊ do things for him/her (what things? Have you talked about it?)
◊ 'personal code', etc.

Try to elicit the ways in which each pair can work together to be supportive rather than over-protective, e.g:

⇒ Which kind of support is comforting?

⇒ Doing too much can be humiliating. What do each pair feel comfortable with?

⇒ Explaining to other people. How will each pair manage the 'does he take sugar phenomenon?' Which kind of answer do they prefer?

"He's getting on very well."
"Why don't you ask him?"

Encourage each couple to work out an answer that they are both comfortable with.

⇒ What about preparing to go out?

⇒ If there is a social situation such as a meal to which you have been invited, is it helpful for your partner to discuss dietary needs? *(NB: each couple may choose to manage this differently.)*

- **Personal code**

  " It is helpful to have a (discreet!) pre-arranged signal which the partner can recognise, e.g: smoothing hair back, tapping nose to indicate when you want to be rescued, go home, have any problem where you want some help.

  Similarly, your partner can have a simple signal for "are you all right?""

  Demonstrate an example of this; again this can be light-hearted, but you want to end up with a useful tool, so it must not be too obvious.

- **Homework assignment**

  Each couple to read the '*Making the Change*' booklet.

  Each couple to work out their own personal code.

Session 5 – Talking to others, comments and questions

Resources: *'Everybody's staring at me' booklet*
'Making your face work for you' booklet
Overhead slides

⇒ Patient perspective
    Talking to close family
    Learning to disclose
    Talking to children

⇒ Partner perspective
    Learning to listen
    What to say
    What not to say

⇒ Meeting other people

⇒ Preparing for questions

⇒ Managing intrusion

5.i Recap on last session, debrief on homework and outline of today

Put up Overhead 2 of REACH OUT.

" In the last session, we watched the video of REACH OUT, and worked out how you can use your communication skills like tools to help you to take the initiative in social situations.

We also thought about the ways in which your partners can help you when you are out together."

Debrief on 'Making the change' booklet. Were the examples helpful? Have they worked out a private code? Does anyone need help to do this?

5.ii Patient Perspective

- **Warm-up exercise**

  " I want you to imagine that the person sitting next to you is someone who works in a shop, and I want you to ask them whether they sell a certain item. It can be anything you like, but I want you to think about REACH OUT as you do this, and present yourself in a confident and assertive way."

  ◊ *Trainer begins*: "Good morning. I am looking for a pair of lurex socks….."

  As with all the warm-up exercises, try to break any tension, keeping the exercise light-hearted. Praise each participant, commenting on the positive aspects of what they do before suggestions for improvement.

  ⇒ *Look for*
  - ◊ good eye contact
  - ◊ smile
  - ◊ posture
  - ◊ firm, assertive statement
  - ◊ clearly expressed request, etc.

- **Talking to the family**

  " One of the most important things in making a good recovery after surgery is 'social support'. We know that people do better if they have a supportive family, but we also know that we are not very good in helping families to provide that support.

  I want to spend some time today in thinking about the ways in which your partner can help you. We started this last week in talking about support when you go out and meet other people, but I want to think more about just what support is."

  Using flip chart, Heading: It's good to talk! *try to generate examples under each heading. Here are the kind of things that might be suggested, but this will vary from group to group.*

PATIENT PERSPECTIVE: IT'S GOOD TO TALK!

Why is it good to talk?	**What are the worries about talking?**
Prevents misunderstandings	Don't want partner to worry
Helps partner to know concerns	Talking won't help
Shared experience (a worry shared...)	You just have to put a brave face on
Other people can often help	Other people are too busy
	People don't know what to say

Try to promote a discussion of these issues. What do partners feel? What are the barriers? Good and bad times to talk. Choosing the time carefully so that people aren't doing something else. Recognising that your partner may need to talk. It's okay to be upset.

- **Talking to Children**

  What do you say to children?

  Elicit discussion. Children can be very curious and ask questions. Try to develop idea of answering children's questions honestly when they arise, without a lot of extra detail unless prompted.

5.iii Partner perspective

- **Learning to listen**

  Use flip chart, try to elicit examples under this heading.

  How do you know if someone is listening?

  ◊ Attention (not doing other things!)
  ◊ Eye contact
  ◊ Asking questions
  ◊ Sitting near, etc.

" The focus is on making a clear commitment to listen. Trying to respond when prompted, but it is okay to say, "I really want to talk to you about this. Can we sit down properly once I've finished getting tea?""

Using the flip chart, try to elicit examples under these two headings.

PARTNER PERSPECTIVE: LEARNING TO LISTEN!

What can you say?	**What not to say**
How can I help?	It could have been worse
What can I do for you	Look on the bright side
I want to understand...	Other people are far worse off
I want to know how you feel	It's no good dwelling on it
We can cope with this together	It's up to you now
Take all the time you need	You should be getting out and about by now

Try to get group to generate ideas helpful to them.

E.g: In general, it is better not to offer solutions before prompting for more information. Don't dismiss people. Don't compare with others. Avoid telling other people how they should be managing. Instead try to ask how you can help. Don't assume that people feel better when physical scars have healed etc.

"I want to understand" and "I wish you would tell me how you feel" are better than "I understand" or "I know how you feel". Unless you have been in the situation yourself, you probably don't know...

5.iv Meeting other people

" At some point, you will feel ready to resume the everyday activities that involve meeting other people – everything from buying a paper, to going back to work.

If surgery has resulted in altered appearance or in difficulties with speech, it is worth spending some time thinking about how you will respond to peoples' questions and comments."

- **Preparing for questions**

Overhead 1 ***SCARED model***

" Remember, people may be uncertain or SCARED. They may be curious about you but not feel able to ask. Sometimes, this is the reason that people stare. On the other hand, they may be very direct and ask you what happened to your face? In any situation, you can use your REACH OUT skills to put them at ease and learn to answer questions in the way that suits you."

Overhead 2 ***REACH OUT model***

" First of all, let's think about some ways of answering this question."

Overhead 3 ***What happened to your face?***

Cover answers whilst group generates responses.

Use flip chart to collect answers. Try to collect a range, both helpful and not helpful, e.g: "mind your own business".

Uncover Overhead 3.

" These are three ways of answering the question, but you can see that we have put them under three headings:

⇒ basic information, and close subject

⇒ basic information and general comment

⇒ very full answer

OVERHEAD 3

Excuse me, I hope you don't mind me asking, but what happened to your face?

"I have just had an operation for cancer, but you don't want to hear all about that."

⇒ *Closed: the message is clear, end of subject.*

"I have had an operation for facial cancer. It is a pretty rare condition, but luckily we live very near the specialist unit."

⇒ *Confident, at ease with subject and encouraging a discussion of the issues in general rather than personal terms.*

"I have just had an operation for cancer. It is amazing what these plastic surgeons can do. They took a graft from my leg... etc."

⇒ *Confident, clearly eager to discuss every detail.*

Organise group responses under the same headings. Which one does each person prefer?

" You can choose which sort of level of detail suits you. Most people are happy with a very brief explanation. Remember not to write the script that says they are hostile. They are interested, exactly as you would be yourself."

- **Taking the initiative**

  Overhead 4

  " If people do not ask about your face, then you have the choice of bringing it into the conversation on your own terms. This will give you total control over the situation, and it often works better than waiting for the 'social ambush' later on when everyone has had a drink and suddenly feels bolder!"

- **Managing intrusion**

  What if people are staring?

  Start with questions about staring. Is it likely to happen? Has anyone experienced it? Is it a worry? Try to emphasise the SCARED model and that people are UNCERTAIN as opposed to HOSTILE. Stress the fact that aggressive staring is much more unusual, but may happen occasionally. e.g:

  "There is a difference between the kind of looking involved in communicating with someone, and even the inquisitive curious glance when people meet you for the first time, and the unremitting continuous stare. Your objective in dealing with this, is to demonstrate that you are aware of it, and would prefer it to stop.

  You can start by looking back at your assailant firmly. A smile or a nod demonstrates that you are aware of them, and also that you are normal! If this is not enough, a firm look through narrowed eyes, with a frown conveys displeasure.

  If you decide to say something, you can choose a number of different approaches."

Overhead 5 **Managing staring**

Make the point that there are no right answers. The idea is to develop a response that suits the individual, e.g:

" How you respond depends on what feels comfortable for you in that setting. This will vary. Sometimes it may not bother you. At times you may feel very aggressive, and at other times you may feel like walking away. Having a range of alternative responses is useful; something to match each occasion. Or you may find that one particular strategy is very effective and works for you most of the time. The important thing is to be prepared to try out some of these ideas and put together your own personal set of skills. Each new incident is an opportunity to test out these skills and find out what works for you!"

CHANGING faces
A BETTER FUTURE FOR FACIALLY DISFIGURED PEOPLE

OVERHEAD 4

Taking the initiative

"You have a wonderful tan! One of the problems with skin grafts is that you have stay out of the sun."

⇒ *Confident, not bothered about talking about my face.*

"I see I'm getting the usual furtive stares from the people at the bar. No doubt they are admiring my taste in jackets!"

⇒ *Even more confident, able to make a joke about it. A very successful strategy if you practise it.*

"I am enjoying myself this evening. Often, I find these events difficult because of my face, but everyone seems very friendly tonight..."

⇒ *Confident, self disclosing, and complimentary to the group... a good strategy if you want to meet these people again.*

- How can partners help with managing staring?

  Try to promote a discussion of the role of the partners. They will probably feel quite strongly. Some may suggest physical intervention. Stress the difference between aggression and assertiveness.

- Is it helpful if partners intervene or not? Is it better to leave the response to the individual? Which do they prefer? If it is helpful for partners to intervene, what might they say?

  Try out some responses based on the overhead, being very clear about being verbally assertive not aggressive.

- What about people making comments?

  Introduce this in the same way as for staring, stressing that this is unusual but may happen occasionally. Being prepared involves a range of options:

- "You may occasionally overhear people making remarks, perhaps deliberately intended for your ears, or you may come across people who make rude remarks to your face. What do you do? What does your partner do?"

  Use flip chart to elicit responses such as:

  ⇒ walk away. This kind of person is not worth bothering with

  ⇒ show them that you are

  a) aware of what was said

  b) did not like it

  ⇒ say something to them

<u>Overhead 6</u> **Dealing with intrusive comments**

Emphasise the fact that these are rare events, but it is important to be ready for them As with staring, it is important that each couple decides if it helpful for a partner to intercede, and what should be said.

Practise responses – working on an assertive, non-aggressive reply.

Stress the aim: to develop a way of responding which feels comfortable. It is important that the individual feels comfortable with the response/s.

CHANGING faces
A BETTER FUTURE FOR FACIALLY DISFIGURED PEOPLE

OVERHEAD 5

Managing Staring

"I would prefer it if you did not stare at me."

⇒ *Assertive, simple.*

"Does my face bother you? It doesn't bother me!"

⇒ *Confident, assertive, and clearly labelling your assailant as the one with the problem.*

"You should see what I look like on a bad day!"

⇒ *Confident, humorous.*

"Don't worry, it isn't catching!"

⇒ *Humorous, but making the point that their behaviour is intrusive.*

CHANGING faces
A BETTER FUTURE FOR FACIALLY DISFIGURED PEOPLE

OVERHEAD 6

Dealing with intrusive comments

1. **Walk away**

   ⇒ *Not a cop out! This person is not worth bothering about!*

---

2. **Firm stare**

   ⇒ *Makes it clear that you are aware and dislike it.*

---

3. **Say something**

   "Actually my name is..........................."

   ⇒ *Firm, assertive but not aggressive.*

   "Does my face bother you? It doesn't bother me!"

   ⇒ *(as above, firm and defining the speaker as the one with the problem.)*

   "Very original!"

   ⇒ *Confident, assertive – a put down.*

- **Homework**

  Each couple to finish reading both the cancer and staring booklets.

  Work out between them how to answer the questions:

  ⇒ What happened to your face?

  ⇒ What happened to your wife's/husband's face?

Session 6 – Eating with others

This section includes:

⇒ Eating at home
  Food preparation
  Coping skills

⇒ Eating out
  Planning ahead
  Where to sit
  What to say

6.i Recap on last session, debrief on homework and outline of today

" Last time we talked about talking and listening to each other, and about dealing with other people. We thought about coping with staring or questions from other people, and how partners could help support us."

Debrief on staring booklet. Were the examples helpful?

Use flip chart to write down some of the answers that each couple have worked out to the question "What happened to your face?"

◊ What are the individuals going to say?
◊ What are partners going to say?

Ask each couple to demonstrate their personal code.

6.ii Eating at home

" In this session we want to think about going out to restaurants or eating with other people."

Stress the social side of eating. Eating with others is more to do with sharing the situation rather than eating the food. It is important to work out a way of participating even if you are not eating the same food or even any food. Just being part of the group is important, etc.

" In the same way as you can manage social situations where you have to meet and talk to people, you can manage situations where you are going to be eating with other people. If we think about the concerns that people have about eating, especially with others, we can see how similar they are to concerns about what we look like."

Use the flip chart to generate problems related to eating. Try to elicit feelings as well as physical problems.

⇒ Examples may include:

Practical problems	Makes me feel
Can't eat the same food	Embarrassed
Difficulty chewing	People are staring
Need to use straw for drinking	People make assumptions
Dribbling	Feel anxious
Food falls out of mouth	People may say something
Can't taste food	Want to avoid situation

Stress the importance of thinking about how these problems can be managed by thinking about them in advance, developing some coping strategies, and then taking the initiative to put them in place in various situations.

Look at ***coping strategies*** *first. What do they do at home?*

- **Food preparation**

Which foods are easiest to eat? *(ask each couple to list five items)*

Which foods are hardest to eat? *(ask each couple to list five items)*

How can food be prepared to make it easier to eat? *(elicit information)*

◊ by boiling rather than roasting
◊ by sieving or liquidising
◊ by presenting in small quantities
◊ can it be seen? – dark food on light plate / light food on dark plate.

- **Coping skills**

What other things are helpful?

◊ utensils or straws
◊ napkin or tissues to hand

Where do they sit?

Introduce the idea that position can make people feel less exposed.

◊ sitting beside someone instead of directly opposite
◊ sitting with the non-affected side of the face next to them
◊ sitting at the corner rather than in the middle
◊ are they more comfortable at a round or square table?

Who sits with them?

◊ partner?
◊ family?
◊ eat alone?

It is important not to put pressure on anyone who feels unable to eat in front of other people. However, it is useful to point out that this does not mean giving up on family mealtimes, social eating etc. Try to elicit alternatives e.g:

⇒ sit with family group whilst they are eating, but eat before or afterwards

⇒ eat only a selection of what they are eating

⇒ sip a drink, etc.

6.iii Eating out

Summarise the coping strategies above, e.g:
" You can see that we can produce quite a long list of ways in which we can make it easier to manage eating at home. Eating away from home can seem more challenging because of the unfamiliarity of the situation and other people, but we can produce a similar list of ways in which we can make it easier."

Use flip chart to write down suggestions, e.g:

- **Planning ahead**
  - ◊ Start with a place where you have been before
    Familiar places will be easier than somewhere that is completely strange.
  - ◊ Choose somewhere with a range of food that you can manage
    Avoid fast-food chains such as pizza houses which limit your choice.
  - ◊ Take straws etc. with you
    This will save having to ask for things that draw attention to your difficulties.
  - ◊ Go with close friends or family
    Don't arrange to meet someone new for the first time in a situation where you don't feel comfortable.
    Remember your personal code.
- **Where to sit**
  - ◊ Choose somewhere where you can book a table
    Ask to sit in a corner rather than in the middle of the room, next to a wall or whatever is preferred. If you have a choice over table shape, ask for the one you prefer.
  - ◊ Choose where you sit at the table
    Sit with your back to the rest of the room and facing your party. Agree with your partner about where he/she will sit. Remember that people will be speaking. Sit somewhere where you can hear, otherwise you will feel left out of the conversation. This is more important than eating anything!
  - ◊ Leave the food, not the table
    If you don't feel comfortable eating, simply stop, but remain with your friends. Don't avoid the situation.

Try to emphasise the range of things that will help in getting used to the challenge of going out or eating in front of other people. As with dealing with the public in other situations, planning ahead will help. If eating with friends, suggesting some foods or asking not to be treated differently are both options. Most people prefer it if no fuss is made. Partners can be helpful in offering support here.

- **What to say**

  Prepare for possible comments and questions:

  " Be prepared for people to talk about food. This is normal behaviour and not a comment on the fact that you are not eating or find eating difficult. Try to think about some of the things that people might say in advance and think of how you might reply."

  Use flip chart or ask for some examples:

  ◊ Can I get you something else?
  ◊ You haven't eaten anything!
  ◊ You've got to eat you know!
  ◊ What about some ice cream?

  Take the initiative before they get the chance to draw attention to you:

  "You are probably wondering what I can eat. I cannot manage x, but y is fine."
  ⇒ *Confident and at ease with the subject.*

  "Please don't worry about whether or not I am eating or go to any trouble. I would much prefer it if you simply ignore me."
  ⇒ *Confident and assertive.*

  "My wife has recently had some oral surgery. She may choose to eat very little. Please don't fuss over her!"
  ⇒ *Clear and supportive.*

  Use REACH OUT in talking about food:

  "I have eaten quite enough thank you."
  ⇒ *Confident and assertive.*

  "That was delicious. Where did you get the recipe?"
  ⇒ *Assertive but shifting the attention on to the other person.*

"Losing some weight has been about the only advantage of this episode. I don't want to undo all that by living on ice-cream!"

⇒ *Confident and humorous. Don't forget that humour can be very useful for putting other people at ease.*

Try to generate some more suggestions

- **How partners can help**

Try to elicit the kinds of ways that partners would like to help. What does the patient want? How can partners be supportive without taking away autonomy?

Examples of how partners can help in planning include:

◊ reassuring friends and family
◊ booking for meals
◊ suggesting appropriate menus
◊ sitting next to/opposite partner
◊ learning to manage direct questions by using REACH OUT
◊ being aware of partner's needs
◊ respond to personal code.

- **Homework**

Ask each individual to list four things that will make it easier to manage eating.

Ask each partner to list four ways in which they can support this plan.

Next session: Explain the focus of the next session, 'Getting used to going out' in which everyone will work out management plans for everyday situations.

PART THREE: GETTING USED TO GOING OUT

Role play and practising target situations

This is the stage at which you are helping people to put things together and practise some challenging social situations.

The examples given are common everyday situations, but you could ask patients to generate their own. Each is presented as a cartoon featuring Humpty Dumpty to reinforce the nature of the task. These can be used as overhead slides.

Each example is presented as an A3 handout which can be photocopied for each member of the group. The manual contains an annotated version of each (coloured paper) which will help the instructor guide patients through each one.

Back up resources include:

- ◊ 'Making the change' booklet
- ◊ 'Making your face work for you' booklet
- ◊ 'Everybody's staring at me' booklet
- ◊ REACH OUT video

The social situations selected are:

- ◊ Buying a paper
- ◊ Visiting a supermarket
- ◊ Visiting the hairdresser
- ◊ Using public transport
- ◊ Using the telephone
- ◊ Posting a parcel (using a servox)
- ◊ Eating out in a restaurant
- ◊ Going to a party
- ◊ Going swimming
- ◊ Going back to work

For each situation, the patient and partner can work together to produce a management plan using the following headings:

TASK ⇒ TOOLS ⇒ TROUBLESHOOT ⇒ TEST

⇒ Task

Under this heading, the aim is to define the task, and break it down into a series of graded steps. Each step will be practised until the patient is comfortable, before going on to the next step. (See example)

⇒ Tools

Under this heading, the patient and partner consider the tools that they will need to succeed. These include both physical things like what they need to take with them, (Glasses, voice synthesiser) how they are going to dress, as well as problem-solving skills as in REACH OUT, e.g: posture, eye contact.

⇒ Troubleshoot

Under this heading, the patient is encouraged to think about the difficulties that might be encountered. What might be the most worrying aspect of doing this, and what can be done to be prepared? E.g: What is likely to happen? Are people likely to stare or make comments? If I am asked, what do I say? If my partner is asked, do we have an agreed answer? Do we have an agreed signal if I want to go home?

⇒ Test

This is the practice stage. The task is practised regularly and the diary sheet completed. Difficulties are recorded so that they can be discussed and the plan revised.

Not all these situations are necessarily relevant to everyone. It can be useful for people to pick out one or two to work at. However, the paper shop example is a very good first stage for everyone, since a very easy graded programme can be worked out, and it is a regular everyday activity that can be continued.

The supermarket is another useful exercise because it is something that can be practised regularly and includes many of the social difficulties that need to be managed.

Consistent practice is important. Regularly going out to buy a paper means that the patient is practising their social and problem-solving skills every day. This will build confidence and help them to feel able to tackle other social tasks.

- **Completing diary sheets**

  Completing a diary provides a vital record of progress, and indicates when to move on to the next stage. Regular practice is important. Doing a small task every day is better than trying to a challenging task once a week. Use a scale of 0–8 to indicate discomfort.

  Progress is likely to be intermittent. Three steps forward followed by two back. Everyone has bad days! The message is to carry on. Troubleshoot: why did things go wrong? What could be done differently? Try again! Do not move on to a more challenging situation until the individual is comfortable with the simpler task, as indicated by the scale.

Example One: The paper shop

Use the same procedure for each target situation being tackled. The paper shop is worked through here as an example.

Trainer explains the role play sessions to the group as below.

" This is the stage at which we put some of the ideas that we have discussed into practice. We are going to look at some practical situations together and work out how they can be managed. The first example is going to buy a newspaper, and we are going to plan doing this under four headings.

1. First we will look at the **task** and what is involved.
2. Then we will work out what **tools** are needed to do it.
3. Under **troubleshoot**, we will think about what might be difficult about the task or what might go wrong.
4. Finally we will think about **testing** it out."

Trainer distributes paper shop handout to each pair, using the coloured copy as a master.

⇒ TASK

" You are going to go to your nearest paper shop to buy a newspaper. To start with, you can make this as easy as possible, for example, by taking the exact change with you and picking up the paper you want. You don't need to speak. Once you are comfortable doing this, you can plan to make the task more challenging by asking for a different paper or buying something else. You might want someone to go with you the first time you go, and then gradually start doing it by yourself.

Here is an example of how you can start off with a very simple task and build a little more into it every day until you are doing something that might seem very challenging to begin with. Your partner can help you to plan and get started before you tackle the situation on your own."

Day One	*Walk along to papershop with my partner. Partner buys paper.*
Day Two	*Walk along to papershop with partner, buy paper myself.*
Day Three	*Walk along to papershop on my own and buy paper.*
Day Four	*Walk along to papershop and buy paper – wait for change.*
Day Five	*Walk along to papershop and ask for something else in the shop.*

⇒ TOOLS

" You also need to think about the tools that you need to do this task. Thinking over the work that we have done over the past sessions:

- ◊ What are the things are going to help you succeed?
- ◊ Think about the way you present yourself as well as practical issues like what you need to take with you.
- ◊ How can REACH OUT help you?
- ◊ What can you **do** and what can you **say**?"

Write down some of your ideas below:

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Try to encourage each pair to work out some tools between them. Elicit responses from group. Stress posture, eye contact, smile. Discuss verbal strategies, e.g: "Good morning", asking for something clearly. Think about REACH OUT. How are they going to reassure the shop owner? etc.

⇒ TROUBLESHOOT

" What are the things that you think will be difficult about doing this? Write them down below, together with your ideas about how you will manage them. Some examples are given for you to complete but you might have more."

Problem	Solution
Someone might ask about my face	I could say ....
People might avoid looking at me	I could ....
Someone might ask my partner what has happened to me	I could ....
....	....
....	....
....	....

In troubleshooting the session, you need to help people focus on specific difficulties rather than general anxiety such as: "I would feel very worried about doing it"

Try to elicit the specific fear, e.g: "What if someone asked questions or stared?" so that a strategy for dealing with it can be generated.

⇒ TEST

Start with a simple role play which you model yourself. Focus on walking purposefully into shop, posture, eye contact, etc., without speaking. Ask for one couple to role play using a simple request, e.g: asking for a title. A second couple can try dealing with a "What happened to you?" question.

" Now is your chance to try it out. You can start by practising with your partner.

When you feel ready, try the first situation on the list. Make a mental note of the tools that you need, and try it out.

Use the diary on the back of your sheet to record your progress. The scale provides a record of how comfortable you felt when you were in the situation and how pleased you felt with yourself afterwards. (0 equals completely happy, 8 equals very uncomfortable.

Start with the first step on the list and practise until you feel comfortable and then move on to the next. You don't need to rush. You are taking the first steps back to meeting other people again, so take it slowly and steadily.

As you succeed at each stage, you are building your confidence and developing your skills for managing more difficult situations."

Encourage group to practise at home and complete diary records.

Selecting a new task

As each person/couple becomes confident with a task, so they can select another one if they choose to. Everyone should aim to be comfortable with the first five situations on the list.

CHANGING *faces*

A BETTER FUTURE FOR
FACIALLY DISFIGURED PEOPLE

THE
PAPER
SHOP

TASK

You are going to go to your nearest paper shop and buy a newspaper. To start with, you can make this as easy as possible, for example, by taking the exact change with you and picking up the paper you want. You don't need to speak. Once you are comfortable doing this, you can plan to make the task more challenging by asking for a different paper or buying something else. You might want someone to go with you the first time you go, and then gradually start doing it by yourself.

Here is an example of how you can start off with a very simple task and build a little more into it every day until you are doing something that might seem very challenging to begin with. Your partner can help you to plan and get started before you tackle the situation on your own.

On the next page is a suggested plan, but you can write your own in the space provided if you prefer.

Day One	*Walk along to paper shop with my partner. Partner buys paper.*
Day Two	*Walk along to paper shop with partner, buy paper myself.*
Day Three	*Walk along to paper shop on my own and buy paper.*
Day Four	*Walk along to paper shop and buy paper – wait for change.*
Day Five	*Walk along to paper shop and ask for something else in the shop.*

You do not need to move on to the next stage until you are quite comfortable with the one before. You might want to repeat one day several times for example before moving on to the next, or you might want to spend a few days doing the task with your partner before you try it by yourself.

Day One ....

Day Two ....

Day Three ....

Day Four ....

Day Five ....

TOOLS

You also need to think about the TOOLS that you need to do this task. Thinking over the work that we have done over the past sessions, what are the things are going to help you succeed? Think about the way you present yourself as well as practical issues like what you need to take with you. How can REACH OUT help you? What can you do and what can you say?

Write down some of your ideas below:

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TROUBLESHOOT

What are the things that you think will be difficult about doing this? Write them down below, together with your ideas about how you will manage them. Some examples are given for you to complete but you might have more:

Problem	**Solution**
Someone might ask about my face	I could say ...
People might avoid looking at me	I could ...
Someone might ask my partner what has happened to me	I could ...

TEST

Now is your chance to try it out. You can start by practising with your partner.

When you feel ready, try the first situation on the list. Make a mental note of the tools that you need, and try it out.

Use the diary on the back of this sheet to record your progress.

Start with the first step on the list and practise until you feel comfortable and then move on to the next. You don't need to rush. You are taking the first steps back to meeting other people again, so take it slowly and steadily.

Don't worry if you have a 'bad day'. Sometimes it can seem as if you are taking two steps forward and one back. Relax, try again.

As you succeed at each stage, you are building your confidence and developing your skills for managing more difficult situations.

Behaviour Record

DATE	DAILY TASK	HOW LONG I SPENT IN THE SITUATION	HOW WORRIED I FELT (0–8)	HOW PLEASED I FELT ON COMPLETION (0–8)	COMMENTS

CHANGING faces

A BETTER FUTURE FOR
FACIALLY DISFIGURED PEOPLE

THE SUPERMARKET

TASK

You are going to go along to a local supermarket to get some food. Like the exercise with the paper shop, you are going to try to make the task as easy as you can to start with, and then progressively more difficult. Things that will make the task easier include: going with your partner, buying fewer items, going when the shop is least busy etc.

Here is another example of how you can start off with a very simple task and build a little more into each time you do it until you are doing something that might seem very challenging to begin with. Your partner can help you to plan and get started before you tackle the situation on your own.

Try to make a list of visits to the Supermarket, starting with something which is as easy as you can make it and building in a little more each time. The examples below may help, but you can make your own list in the space provided.

Day One	*Go with my partner to Supermarket on a quiet day. Partner does all the shopping.*
Day Two	*Go with my partner to Supermarket on quiet day. Select basket of items and pay for them myself.*
Day Three	*Go on my own to Supermarket on quiet day. Select basket of items and pay for them.*
Day Four	*As above, but make simple comment to check out assistant.*

You do not need to move on to the next stage until you are quite comfortable with the one before. You might want to repeat one day several times for example before moving on to the next, or you might want to spend a few days doing the task with your partner before you try it by yourself.

Day One ....

Day Two ....

Day Three ....

Day Four ....

TOOLS

You also need to think about the TOOLS that you need to do this task. Thinking over the work that we have done over the past sessions, what are the things are going to help you succeed? Think about the way you present yourself as well as practical issues like what you need to take with you. How can REACH OUT help you? What can you do and what can you say?

Write down some of your ideas below:

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TROUBLESHOOT

What are the things that you think will be difficult about doing this? Write them down below, together with your ideas about how you will manage them. Some examples are given for you to complete but you might have more:

Problem	Solution
Someone might ask about my face	I could say ...
People might avoid looking at me	I could ...
Someone might ask my partner what has happened to me	I could ...

TEST

Now is your chance to try it out. You can start by practising with your partner.

When you feel ready, try the first situation on the list. Make a mental note of the tools that you need, and try it out.

Use the diary on the back of this sheet to record your progress.

Start with the first step on the list and practise until you feel comfortable and then move on to the next. You don't need to rush. You are taking the first steps back to meeting other people again, so take it slowly and steadily.

Don't worry if you have a 'bad day'. Sometimes it can seem as if you are taking two steps forward and one back. Relax, try again.

As you succeed at each stage, you are building your confidence and developing your skills for managing more difficult situations.

Behaviour Record

DATE	DAILY TASK	HOW LONG I SPENT IN THE SITUATION	HOW WORRIED I FELT (0–8)	HOW PLEASED I FELT ON COMPLETION (0–8)	COMMENTS

CHANGING faces
A BETTER FUTURE FOR
FACIALLY DISFIGURED PEOPLE

ON
THE
BUS

TASK

You are going to go on a bus journey. Like the exercise with the paper shop, you are going to try to make the task as easy as you can to start with, and then progressively more difficult. Things that will make the task easier include: going with your partner, going a short distance, going outside the rush hour when the bus is least busy etc.

Here is another example of how you can start off with a very simple task and build a little more into each time you do it until you are doing something that might seem very challenging to begin with. Your partner can help you to plan and get started before you tackle the situation on your own.

Try to make a list of bus journeys, starting with something which is as easy as you can make it and building in a little more difficulty each time. The examples below may help, but you can make your own list in the space provided.

Day One	*Go with my partner on a bus at a quiet time. Partner buys the tickets Sit next to partner. Get off after one or two stops.*
Day Two	*Go with my partner on a bus at quiet time. Buy tickets with exact change. Sit next to partner. Stay on bus for longer.*
Day Three	*Go on my own on bus. Offer exact change, go short distance.*
Day Four	*As above, ask for ticket. Stay on bus for longer.*

Continue or make your own list below.

Day One ....

Day Two ....

Day Three ....

Day Four ....

Day Five ....

TOOLS

You also need to think about the TOOLS that you need to do this task. Thinking over the work that we have done over the past sessions, what are the things are going to help you succeed? Think about the way you present yourself as well as practical issues like what you need to take with you. How can REACH OUT help you? What can you do and what can you say?

Write down some of your ideas below:

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TROUBLESHOOT

What are the things that you think will be difficult about doing this? Write them down below, together with your ideas about how you will manage them. Some examples are given for you to complete but you might have more:

Problem	Solution
Someone might ask about my face	I could
People might avoid looking at me	I could
Someone might ask my partner what has happened to me	I could ...

TEST

Now is your chance to try it out. You can start by practising with your partner.

When you feel ready, try the first situation on the list. Make a mental note of the tools that you need, and try it out.

Use the diary on the back of this sheet to record your progress.

Start with the first step on the list and practise until you feel comfortable and then move on to the next. You don't need to rush. You are taking the first steps back to meeting other people again, so take it slowly and steadily.

As you succeed at each stage, you are building your confidence and developing your skills for managing more difficult situations.

Behaviour Record

DATE	DAILY TASK	HOW LONG I SPENT IN THE SITUATION	HOW WORRIED I FELT (0–8)	HOW PLEASED I FELT ON COMPLETION (0–8)	COMMENTS

CHANGING faces

A BETTER FUTURE FOR FACIALLY DISFIGURED PEOPLE

THE HAIRDRESSER

TASK

You are going to go to have your hair cut. Like the exercise with the paper shop, you are going to try to make the task as easy as you can to start with. Things that will make the task easier include: going when the salon is least busy, taking the initiative and telling the hairdresser that this is your first haircut since your surgery, asking if you can have a seat away from the general hubbub of the salon, asking to have the same person to cut your hair each time you go. If speaking is difficult, take a picture of the kind of style you want to reduce the amount of explaining that you have to do, or ask your partner to come with you.

Building a graded series of visits is more difficult here; you can't keep going back to the hairdresser every day, but you can make the task easier by enlisting the support of your partner and hairdresser.

Try using the space overleaf to make a list of things which would make it easier for you to go to the hairdresser. You can use the ideas above, or you may have new ones.

These are the things which will make visiting the hairdresser easier for me:

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TOOLS

You also need to think about the TOOLS that you need to do this task. Thinking over the work that we have done over the past sessions, what are the things are going to help you succeed? Think about the way you present yourself as well as practical issues like what you need to take with you. How can REACH OUT help you? What can you do and what can you say?

Write down some of your ideas below:

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TROUBLESHOOT

What are the things that you think will be difficult about doing this? Write them down below, together with your ideas about how you will manage them. Some examples are given for you to complete but you might have more:

Problem	Solution
I shall feel very self conscious	I can
People might ask me about my operation	I can

TEST

Now is your chance to try it out This is a challenging task and you should give yourself a pat on the back for tackling it. Mirrored and 'beautiful people' places are often difficult places for anyone who has an unusual appearance. However, hairdressers are very familiar with people's problems and imperfections, and generally very sympathetic and supportive. Don't assume they will feel uncomfortable. They will take their lead from you, and if you seen comfortable with the situation, they are likely to be comfortable too.

Use the diary on the back to record how you get on.

Behaviour Record

DATE	DAILY TASK	HOW LONG I SPENT IN THE SITUATION	HOW WORRIED I FELT (0–8)	HOW PLEASED I FELT ON COMPLETION (0–8)	COMMENTS

CHANGING faces
A BETTER FUTURE FOR
FACIALLY DISFIGURED PEOPLE

THE RESTAURANT

TASK

It is your partner's birthday, and you want to go out to a restaurant to celebrate. You feel rather worried about this, but you would also like to be able to go. Planning ahead and remembering all the things that will make it easier will help you to feel more confident. Things that will make the task easier include: choosing somewhere with an appropriate menu, booking a table that is discretely located, choosing where you sit at the table so that you can hear, asking people not to fret about what you are eating, choosing to have one course rather than several etc.

Here is an example of how you can plan ahead in a way that allows you to do something that can initially seem very challenging.

Try to make your own list below of all the things that will help you.

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TOOLS

You also need to think about the TOOLS that you need to do this task. Thinking over the work that we have done over the past sessions, what are the things are going to help you succeed? Think about the way you present yourself as well as practical issues like whether you need to take straws, tissues etc.

Write down some of your ideas below:

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TROUBLESHOOT

What are the things that you think will be difficult about doing this? Write them down below, together with your ideas about how you will manage them. Some examples are given for you to complete but you might have more:

Problem	Solution
Someone might ask about my face	I could say ...
People might avoid looking at me	I could ...
Someone might ask my partner what has happened to me	I could ...
I might be troubled by dribbling	
I might not be able to eat the food	

TEST

Now you are ready to try it out.

This is a challenging situation, and you should really congratulate yourself for doing it. Don't worry if you ate very little. The real aim of eating in a restaurant is a social one. If you participated, then you succeeded.

Think through any issues that went particularly well, or that you feel could have been better managed. Make a note of them for next time.

Remember, you are far more aware of any difficulties that you have than other people are. As you get used to situations like this, you will find your own way of managing them, and start to enjoy them again.

Behaviour Record

DATE	DAILY TASK	HOW LONG I SPENT IN THE SITUATION	HOW WORRIED I FELT (0–8)	HOW PLEASED I FELT ON COMPLETION (0–8)	COMMENTS

CHANGING *faces*

A BETTER FUTURE FOR
FACIALLY DISFIGURED PEOPLE

GOING SWIMMING

TASK

You are going to go swimming. Like the exercise with the paper shop, you are going to try to make the task as easy as you can to start with, and then progressively more difficult. Things that will make the task easier include: going with someone else, going to a pool with which you are familiar, going outside the busiest time, choosing an adult only session. The laryngectomy society run swimming clubs throughout the country; you might want to go with their group.

Here is another example of how you can start off simply and build a little more in each time until you are doing something that might seem very challenging to begin with. Your partner can help you to plan and get started before you tackle the situation on your own.

Try to plan the task, starting with something which is as easy as you can make it and building in a little more difficulty each time. The examples below may help, but you can make your own list in the space provided.

Day One	*Go with my partner to the pool. Watch while partner swims.*
Day Two	*Go with partner to an early morning session.*
Day Three	*Go swimming on my own.*

Continue or make your own list below:

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TOOLS

You also need to think about the TOOLS that you need to do this task. Thinking over the things that you know will help you to present yourself in a positive way, what are the things that are going to help you succeed? Think about the way you present yourself as well as practical issues like whether you need to protect your trachesostomy site.

Write down some of your ideas below:

....

....

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....

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TROUBLESHOOT

What are the things that you think will be difficult about doing this? Write them down below, together with your ideas about how you will manage them. Some examples are given for you to complete but you might have more:

Problem	**Solution**
People might stare at me	I could return their gaze confidently ...
Someone might ask my partner what has happened to me	I could say ...
Someone might ask about my face	I could say ...

TEST

Now is your chance to try it out. You can start by practising with your partner.

When you feel ready, try the first situation on the list. Make a mental note of the tools that you need, and try it out.

Use the diary on the back of this sheet to record your progress.

Start with the first step on the list and practise until you feel comfortable and then move on to the next. You don't need to rush. You are taking the first steps back to resuming your old hobbies, so take it slowly and steadily.

As you succeed at each stage, you are building your confidence and developing your skills for managing more difficult situations.

Behaviour Record

DATE	DAILY TASK	HOW LONG I SPENT IN THE SITUATION	HOW WORRIED I FELT (0–8)	HOW PLEASED I FELT ON COMPLETION (0–8)	COMMENTS

CHANGING faces

A BETTER FUTURE FOR
FACIALLY DISFIGURED PEOPLE

THE POST OFFICE

Managing speech difficulties when posting a parcel or buying a book of stamps

TASK

You are going to go to the Post Office to post a parcel or buy a book of stamps. This is a challenging exercise for someone who has speech difficulties, for the following reasons:

- the post office is often busy with a queue
- people in the queue tend to look at everyone else
- people my be curious if they see or hear something unusual
- glass barriers can make communication more difficult (although the people who work behind them often become very good at lip reading.)

Like the other exercises in this section, making the task easier depends on starting more simply and moving on to the more difficult aspects. Things that will make the task easier include:

- going with your partner,
- going when the post office is less crowded
- deciding in advance which way you are going to communicate (starting off by using a pencil paper may give you more confidence as you get used to other people again.)
- if you are using your own speech, or a voice synthesiser, decide on a good opening sentence. E.g: "Please listen carefully, I've had an operation on my throat."

Here is another example of how you can start off with a very simple task and build a little more into each time you do it until you are doing something that might seem very challenging to begin with. Your partner can help you to plan and get started before you tackle the situation on your own.

Try to make a list of things that you do at the post office, starting with something which is as easy as you can make it and building in a little more difficulty each time. The examples below may help, but you can make your own list in the space provided.

Day One	*Go with partner at a quiet time. Pick up pension or something that does not involve speech.*
Day Two	*Go with partner at quiet time. Buy stamps using notebook and pencil.*
Day Three	*Go on my own. Buy stamps using notebook and pencil.*
Day Four	*Go with partner. Talk to partner in queue. Ask for stamps using good explanation.*
Day Five	....
Day Six	....

Continue or make your own list below:

....

....

TOOLS

You need to think about the TOOLS that you need to do this task. Thinking over the work that you have learned about, what are the things are going to help you succeed? Think about the way you present yourself as well as practical issues like whether you need to take a notebook and pencil.

Write down some of your ideas below:

....

....

....

TROUBLESHOOT

What are the things that you think will be difficult about doing this? Write them down below, together with your ideas about how you will manage them. Some examples are given for you to complete but you might have more:

Problem	**Solution**
People might stare at me	I could reassure them by ...
People might not understand me	I could say or do ...
Someone may ask me or my partner why my voice is different	I could say...

TEST

Now is your chance to try it out. You can start by practising with your partner.

When you feel ready, try the first situation on the list. Make a mental note of the tools that you need, and try it out.

Use the diary on the back of this sheet to record your progress.

Start with the first step on the list and practise until you feel comfortable and then move on to the next. You don't need to rush. You are taking the first steps back to meeting other people again, so take it slowly and steadily.

As you succeed at each stage, you are building your confidence and developing your skills for managing more difficult situations.

Behaviour Record

DATE	DAILY TASK	HOW LONG I SPENT IN THE SITUATION	HOW WORRIED I FELT (0–8)	HOW PLEASED I FELT ON COMPLETION (0–8)	COMMENTS

CHANGING faces
A BETTER FUTURE FOR
FACIALLY DISFIGURED PEOPLE

GOING TO A PARTY OR PUB

TASK

You are going to a party (or down to the pub). Like all the exercises, you are going to try to make the task as easy as you can by working through the things that are going to make it easier for you, what can go wrong etc. Things that will make the task easier include: going with your partner, presenting yourself in a positive way through your dress, posture etc., working out how to take the initiative before people judge at face value, and preparing for questions.

Before you tackle this kind of social situation, it is important to have worked through some of the earlier exercises such as going to the paper shop. These will help you to become accustomed to other people in a gradual way.

You might still find it helpful to tackle this kind of large social event in stages if you can eg:

Step One *Have a small group of friends round to your home.*

Step Two *Go to the pub at a quiet time with your friend or partner.*

Step Three ....

Step Four ....

Continue or make your own list below.

....

....

....

TOOLS

You also need to think about the TOOLS that you need to do this task. Thinking over the work that we have done over the past sessions, what are the things are going to help you succeed? Think about the way you present yourself as well as practical issues like whether you need a notebook and pencil, drinking cup, straws, etc.

Write down some of your ideas below:

....

....

....

....

....

TROUBLESHOOT

What are the things that you think will be difficult about doing this? Write them down below, together with your ideas about how you will manage them. Some examples are given for you to complete but you might have more:

Problem	Solution
Someone might ask about my face	I could say ...
People might avoid talking to me	I could ...
Someone might ask my partner what has happened to me	I could ...
I might feel that people are staring at me	I could ...

TEST

Now is your chance to try it out. You can start by socialising with your partner.

Make a mental note of the tools that you need, and see how you get on.

Use the diary on the back of this sheet to record your progress.

It can help if you try to stand back from this kind of large social event, and treat your experience a bit like an experiment. If you feel slightly uncomfortable to begin with, don't give up. Some things will go very well, and other things will not be so successful, but may give you some ideas about managing in a rather different way. There is no such thing as failure, only feedback! You don't need to rush. You are taking the first steps back to meeting other people again, so take it slowly and steadily.

As you succeed at each stage, you are building your confidence and developing your skills for managing more difficult situations.

Behaviour Record

DATE	DAILY TASK	HOW LONG I SPENT IN THE SITUATION	HOW WORRIED I FELT (0–8)	HOW PLEASED I FELT ON COMPLETION (0–8)	COMMENTS

CHANGING faces
A BETTER FUTURE FOR
FACIALLY DISFIGURED PEOPLE

USING THE TELEPHONE

TASK

You are going to use the telephone. Many people find the prospect of answering the phone or ringing someone else up quite worrying, but it is actually something that can be made much easier by taking the initiative and getting your message across to the operator first. Like the exercise with the paper shop, you are going to try to make the task as easy as you can to start with, and then progressively more difficult. Things that will make the task easier include: using the phone first just to listen, talking to your partner on the telephone and getting their opinion about what you sound like, making a simple request, making a more complicated request. The most important thing is to take the initiative by asking the person at the other end to listen to you carefully, and explaining why.

Here is another example of how you can start off with a very simple task and build a little more into each time you do it until you are doing something that might seem very challenging to begin with. Your partner can help you to plan and get started before you tackle the situation on your own.

Try to make a short list of calls that you can make, starting with something which is as easy as you can make it and building in a little more each time. The examples below may help, but you can make your own list in the space provided.

Day One	*Get used to the phone by ringing up a recorded message (e.g. talking clock, what's on at the local cinema).*
Day Two	*Talk to partner from another phone, and rehearse your explanation, and then practise by checking train times.*
Day Three	*Ring up local station and ask time of next train to London.*
Day Four	*As above, but ask for return times too.*

or make your own list below:

....

....

....

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....

TOOLS

You also need to think about the TOOLS that you need to do this task. From your knowledge of the things that will help you to present yourself in a positive way, what are the things that are most important in helping you with this task? Think about what you are going to say (write it down) and how you are going to say it.

Write down some of your ideas below:

....

....

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....

....

TROUBLESHOOT

What are the things that you think will be difficult about doing this? Write them down below, together with your ideas about how you will manage them. Some examples are given for you to complete but you might have more:

Problem	Solution
Someone might ask me to speak louder	I could say ...
People might make assumptions	I could say ...
Someone might ask what has happened to me	I could say ...
Someone might put the phone down	I could ...

TEST

Now is your chance to try it out. You can start by practising with your partner.

When you feel ready, try the first situation on the list. Make a mental note of the tools that you need, and try it out.

Use the diary on the back of this sheet to record your progress.

Start with the first step on the list and practise until you feel comfortable and then move on to the next. You don't need to rush. You are taking the first steps back to talking to other people again, so take it slowly and steadily. If you find that people have difficulty understanding your explanation, try and make it more simple. Your partner can help by listening to you on the phone and telling you whih parts of the message are unclear.

As you succeed, you are building your confidence and putting together the skills that you will need to be more and more independent.

Behaviour Record

DATE	DAILY TASK	HOW LONG I SPENT IN THE SITUATION	HOW WORRIED I FELT (0–8)	HOW PLEASED I FELT ON COMPLETION (0–8)	COMMENTS

CHANGING faces
A BETTER FUTURE FOR
FACIALLY DISFIGURED PEOPLE

BACK
TO
WORK

TASK

You are going back to work. Like all the exercises, you are going to try to make the task as easy as you can by working through the things that are going to make it easier for you, what can go wrong etc. Things that will make the task easier include: presenting yourself in a positive way through your dress, posture etc., working out how to take the initiative before people judge at face value, and preparing for questions. Working out a gradual return rather than starting with a full day is also a good plan if your employer can arrange this.

Reading the Changing Faces booklet: *Managing disfigurement in the workplace* will give you some ideas about preparing for work again.

Before you think about returning to work, it is a good idea to have worked through some of the more simple exercises such as buying a paper, using public transport, eating in public etc. These will help you to get used to being with people again in a gradual way.

This list gives some ways in which you can plan your return to work. Continue this, or make your own list below:

Step One	*Work through some of the other exercises to increase my confidence.*
Step Two	*Build up my daily activities such as shopping, hobbies, etc.*
Step Three	*Arrange to go in to work for a casual visit.*
Step Four	*Start work mornings only.*
Step Five	…………………………………………………………………………………………
Step Six	…………………………………………………………………………………………

Continue or make your own list below:

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TOOLS

You also need to think about the TOOLS that you need to do this task. Thinking over the work that you have learned about, what are the things are going to help you succeed? Think about the way you present yourself and what you are going to say rather than issues like the kind of work that you will be doing.

Write down some of your ideas below:

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TROUBLESHOOT

What are the things you think will be difficult? Write them down, together with your ideas about how to manage them. Some examples are given for you to complete but you might not think that these apply to you or you might have more:

Problem	Solution
Someone might ask about my face	I could say ...
People might avoid talking to me	I could ...
Someone might ask other people what has happened to me	I could ...
I might feel that people are staring at me	I could ...
I might feel very tired and unable to cope	I could ...

TEST

You may feel very apprehensive about going back to work. This is completely understandable after any long absence, and you are not unusual. The key to things going well lies in being well prepared, and if you have worked through some of these *Changing Faces* exercises, and practised some of the everyday tasks in a gradual way, then you are well prepared for this next step.

Don't expect things to run like clockwork to start with. You may have a brilliant day followed by one where you feel very tired or can't concentrate on what you are doing, or simply feel that facing other people is too difficult. Try not to let this intermittent progress put you off!

Use the diary on the back of this sheet, to record your progress. This can help you to stand back and treat your experience a bit like an experiment. If you feel slightly uncomfortable to begin with, don't give up. Some things will go very well, and other things will not be so successful, but may give you some ideas about managing in a rather different way. There is no such thing as failure, only feedback! You don't need to rush. You are taking the first steps back to resuming your lifestyle, so take it slowly and steadily.

Behaviour Record

DATE	DAILY TASK	HOW LONG I SPENT IN THE SITUATION	HOW WORRIED I FELT (0–8)	HOW PLEASED I FELT ON COMPLETION (0–8)	COMMENTS

PART FOUR: OVERVIEW AND FURTHER PLANS

Section 1 – Evaluation

Since this programme is a new initiative, it is vital to obtain some information from patients about whether or not this kind of input is useful, both in order to find out the strengths and weaknesses of the programme, but also to identify whether or not there are other issues of importance to the individual. The easiest way to do this is by means of standardised assessment before and after intervention.

1.i Tools

Rating scales are included in the appendix. These include the EORTC QLQ - H&N35 quality of life measure, the Social Avoidance and Distress scale, the Derriford Appearance Scale (short form) and the Hospital Anxiety and Distress Scale. These scales are completed both before and after intervention. A short questionnaire has been added to the post intervention schedule to gain some qualitative information about the pack. The schedules look long, but do not take too long to administer.

1.ii Have the objectives of the programme been met?

Completion of the rating scales will answer the following questions and therefore indicate whether the main objectives of the pack have been met, i.e:

- Have these resources made it easier for the patient to develop his/her coping skills to a level which allows them to manage social situations effectively. Has this had an impact on their quality of life?
- Have relatives (where relevant) found it helpful to be involved in rehabilitation as an active participant?

Section 2 – Who needs further help?

Although Changing Faces data suggests that most people with disfigurement arising from a variety of causes benefit from this kind of programme, there are always those who need further help. This programme has a specific focus on the management of social situations, but individuals may have other areas of concern, or they may have psychiatric symptoms which require treatment. Identifying those for whom additional support is needed is critical.

2.i Psychological assessment

The only person who can make a psychological assessment of a patient is someone who has been trained to do it. However, there are things that can help to identify those people for whom this kind of further support is needed.

- Although depression and low mood are normal reactions to a cancer diagnosis, persistent low mood for longer than two weeks is considered a significant symptom, and psychiatric referral should certainly be considered.
- Depression is characterised by feelings of hopelessness and guilt. People have diminished enjoyment and interest in life, become socially withdrawn and may admit to thoughts of suicide. There is no evidence that asking people whether they have thoughts of harming themselves 'puts the idea into their heads', and a tactfully worded question can be a valuable indicator of the need for help.
- Depressed patients often look depressed. Lack of care with appearance, a fearful or worried expression and psychomotor retardation – slowness in moving or responding to questions – are all significant.
- Another way of screening patients, particularly useful for people who feel they lack the clinical skills or experience to assess the patient's behaviour or ask the right questions, is to use a standardised tool. Those designed for a hospital population take account of illness-related factors in their development and are the most suited to this group. The best standardised and most easily administered is the Hospital Anxiety and Depression Scale (Zigmond and Snaith 1983).
- Whilst lack of social support and poor coping skills predict poorer outcome after surgery, it is important to remember that size and location of disfigurement alone are not reliable indicators of distress. Disfigurement combined with dysfunction is a more reliable predictor of poor quality of life, but it is important to challenge

assumptions that patients with a poor aesthetic outcome are the most at risk. However, where there is the slightest doubt about a patient's mental health, referral to a specialist resource should always be made.

- Finally, it is worth noting that whilst it is pointless to try to continue this kind of interactive programme with someone who is significantly depressed and unable to motivate themselves into taking part in any of the exercises, the setting of simple goals and gradual introduction of more challenging tasks can be a very helpful part of treatment for depression. It is therefore possible that some of the exercise sheets, or booklets that challenge negative beliefs (such as the one on staring) could be a useful resource for individual sessions supervised by mental health professionals.

2.ii Loss and Bereavement

The overwhelming experience of altered body image – whether a change in looks, speech or behaviour is commonly reported in terms of bereavement. Patients often describe the process of coming to terms with the loss of part of themselves in a similar way to describing the loss of someone close to them. Grieving for the lost self is an important part of the process of recovery.

This programme does not attempt to provide a framework for managing issues of loss and bereavement since it is considered that counselling in an non-directed setting is a more appropriate way of helping people to resolve these issues than the directive problem focused approach. However, the group setting is valuable in allowing people to share feelings and to find out that these are normal and will become resolved over time. Making space in the group for people to set their own agenda is important, and this can be scheduled either at the beginning or end of the groups outlined in this programme.

Putting a time frame on these issues is impossible. Some people may come to terms with change very quickly whilst others find that adaptation takes months. This can often be a very real issue for relatives who expect the resolution of emotional issues to match the process of physical healing. Counselling may be particularly helpful in providing an alternative or balance to the problem solving or solution driven model and where unresolved feelings of loss persist.

2.iii Close relationships, sex and intimacy

Not surprisingly, given the relationship between physical attractiveness and sexual desirability, people may feel very anxious about whether they are still attractive to their partners after treatment, or whether they will ever make a relationship with anyone if they are not in a current relationship.

Partners too may be anxious about how they are going to feel, whether their sex life is going to end or how long it will be before it is appropriate to think about making sexual overtures.

This is typically an area that is avoided by health professionals too. Nurses recognise it as important, as a likely concern for their patients, but feel unskilled at helping them to manage their concerns.

This section therefore provides a framework for offering support to patients. It is included in this section of the manual for two reasons. First that it will not be a concern for everyone, and second because it is a topic which is more appropriately managed with couples rather than in a group.

- **Raising the issue**

  Whilst some people will be able to raise this as a concern e.g: "I'm worried that I don't feel attractive any more", others may not know how to talk about such personal issues. One way around this is by direct questioning, but a more indirect approach can also be successful. The 'Cancer' booklet in the pack includes an example of concerns about sexual attractiveness (*Mary, page 13*), and this can be used as a focus for discussion, e.g: "Are there any examples that you felt were particularly relevant for you?"

- **Talking about sex and intimacy**

  If the couple is unable to talk about the issue, then they are unable to reassure each other and may anticipate problems that are not there. Anxiety in itself may then lead to sexual problems. However they may not want to talk to anyone else about issues that they feel are personal. If a couple acknowledge concerns but do not want to speak to a third party, they may find written information helpful. The handout overleaf gives some very basic information, and there is also relevant information produced by voluntary organisations such as the Laryngectomy Association, CancerBacup etc. Where couples are looking for help and advice, the following framework may be useful:

- **Treat problems as joint problems**

  This does not mean that you always see the couple together, but it does mean that you need to speak to both partners about their feelings so that you understand each point of view. Encourage each partner to express their feelings honestly to each other, either at home, or with you there. Your role is to facilitate their discussion, but your own behaviour is very important. You need to appear confident and at ease, and to use unambiguous and colloquial sexual language without embarrassment. In modelling this approach to sexual behaviour in a relaxed way, you are helping the couple to do the same and to talk about the issues that concern them. You are also providing them with the language to do so.

  (If you don't feel that this is something that you feel at ease with, then you might consider referral to a Clinical Psychologist. Management of sexual dysfunction is a part of their training and most psychologists in health settings can offer this kind of intervention.)

- **Identify and challenge negative beliefs**

  The commonest belief is the one that the individual is no longer attractive following surgery. In challenging this, it is helpful to focus on the characteristics that each partner admires in the other. Guide the discussion to personality attributes if you need to, although these are usually the attributes that individuals automatically describe. You can then point out that the things that are admired in other people are less to do with appearance and more to do with personality, kindness, sense of humour and so on.

  A second common negative belief is that there is no point in making any effort with appearance. Having nice clothes, a good hairstyle etc. are even more important in projecting a positive image. Other people respond to the whole package, not simply to the face.

  Beware of sounding dismissive; your aim is to acknowledge and show that you understand the individuals beliefs, but that there is an equally valid and more positive way of looking at things.

- **Reduce anxiety**

  No-one feels like sex if they are anxious. Unfortunately, those aspects of physical contact which can be reassuring and comforting at a time when patients are feeling very traumatised, can also be interpreted as precursors to sex. Behaviour which is usually anxiety reducing for most of us, kissing, cuddling etc., can therefore generate anxiety and resentment. The way around this is to set clear boundaries for a period of time. Couples can agree that for the moment, they will limit their love making and not consider sexual intercourse. Psychologists often set tasks for patients to move them gradually on from this stage once they feel comfortable. They might progress from general touching and stroking of non-genital areas to more intimate contact, again without intercourse and then finally on to full sexual contact. However, for this kind of patient population, an explanation of the *principle* of gradually get used to each other again is usually enough.

- **Educate**

There are things that are going to be different following surgery, particularly with regard to loss of sensation and movement in the face. Focusing attention on those areas of the body that retain sensation is important, discovering what is enjoyable and what is not, experimenting with different coital positions are all things that will make sex more rewarding. The handout discusses other management ideas and can be offered as back up to what is discussed in individual sessions.

Sexual activity is an important part of some couples' lives, but it is not important for everybody. Some couples are very happy to limit or reduce their sexual activity as they get older, so it is important not to assume problems which are not there. Similarly, a large proportion of happily married couples who describe their sex life as good, report problems of arousal, anorgasmia, erectile incompetence and ejaculation problems.

Where real problems exist, for example, where a partner may be unable to accept the degree of disfigurement in a patient, it is useful to refer for specialist help. Very commonly, the relationship may be insecure for additional reasons, and a full assessment of these with appropriate counselling is the best way ahead.

In summary therefore, the goal for intervention with this patient group is to ensure that a happy sexual relationship is not impaired by a failure of communication, lack of appropriate information or inaccurate beliefs. For most couples, this is something that can be achieved in individual sessions using the framework above, or through the provision of written information.

- **What about patients who do not have a partner?**

This group of people do have a more difficult task because of the importance of looks in initial contact. Making sure that they make the best of their appearance in the way that they dress, and that they take the initiative in meeting people are very important. Above all, it is important to look for friendship first and not for an instant intimate relationship. The Changing Faces guide 'Meeting new people, making new friends', included in the pack, discusses these issues in more depth. This can be used as a focus for discussion or offered as information to take home.

Sex and intimacy after head and neck cancer

Where treatment involves an alteration in appearance, it can take a long time to adjust to your new looks, and it is quite normal to worry about whether or not you are still attractive to your partner. Even where your appearance has altered very slightly, these feelings are still common, and it can be difficult for partners to understand why such a small thing (to them!) is such a big thing for you!

Sadly, many people worry about these issues without being able to talk about them with anyone else. This sheet discusses some the questions people often ask. The idea is to provide you with information, but also to encourage you and your partner to discuss the things that concern you.

- **Am I still attractive?**

  Looks are important when we meet people for the first time, but they become increasingly less so as people build a relationship. If you and your partner love each other, then a change in your appearance is far less important than you might think. Talk about this honestly if you can. Many people worry about this unnecessarily, and withdraw from their partners, whilst their partners may not even see it as an issue. Some partners even report feeling hurt or angry at the idea that their feelings may have cooled.

  Although it can be difficult, it is important to carry on looking after yourself in exactly the way you have always done. What you wear, how you have your hair cut etc. all send powerful messages about how you think about yourself. If you don't believe that you are worth bothering about, other people will find it harder to think in a positive way about you.

  Don't write the script that says that you are no longer sexually desirable! Many of the difficulties that people have arise over misunderstandings, and when people feel anxious, they don't feel like sex.

- **When is my interest in sex going to return?**

  There are no rules for how you are going to feel after treatment, but people who have experienced any serious illness and the worry of treatment, often find that they lose interest in sex for a while. But this is often the time when people like to feel that they have someone close to them. You might want to hold your partner's hand, cuddle up to them or simply touch and stroke them.

Feeling comfortable with this kind of physical closeness without it necessarily leading on to sex is important. It allows you to feel close to your partner and your partner to feel close to you, in a way that minimises anxiety. To start with, it can be very helpful if you and your partner agree that for a few weeks – or how ever long you choose, you are going to limit love making to this kind of physical contact.

- **I don't want to hurt my partner; is it okay to touch her face?**

  Part of a happy and enjoyable sexual experience is telling your partner what you like and what you don't like.

  After surgery to the face, there are often parts of the skin that are numb, and your partner may prefer you to focus stroking and caressing on those parts of the face which they can feel, or on other parts of their body. You might want to swap over the side of the bed that you normally sleep on, so that when you face each other, you will automatically touch the skin that still has sensation.

  Some things may feel very strange to begin with. If your partner has a tracheostomy (a breathing hole in his/her neck), you will feel their breath on your neck instead of on your face. Some people diffuse this by wearing a light gauze dressing over their neck, but other people find that they just get used to it.

  Kissing may be physically difficult too. A kiss requires a complex interaction of several muscles and depends on sensitivity in the lips for pleasure. Your partner may find kissing difficult, they may still have sensation even if they cannot move their mouth very well, or they may have it on one side of the mouth. Experiment, and tell each other what you like.
- In some ways, you are getting to know your partner' body again, and this can be very pleasurable and exciting for both of you provided you are open and honest with each other.

- **I don't want my partner to see me without my prosthesis**

  Some people prefer it if their partner does not see them without their prosthesis, and some people don't mind. In fact some people have described the act of removing or cleaning a prosthesis in front of a partner as something that heightens the sense of intimacy between them. However, this obviously depends a lot on what kind of surgery has been done, and also on how interested their partner is in what is underneath it. There are no right or wrong decisions, and you will decide what is right for you.

- **We don't seem to be able to talk about our sexual concerns. Is there anyone who can help us?**

  Yes there is. You can talk to the Head and Neck Nurse working on your team. If you still feel that you need more help, then ask to see a Clinical Psychologist. You may feel that these are personal matters which are embarrassing to speak about, but for health professionals, sexual feelings and behaviour are an important aspect of their training and clinical work.

  You can also get help from some of the organisations listed in the 'Cancer' booklet e.g: *CancerBacup* and *Changing Faces.*

Section 3 – Other organisations offering help and advice

CancerBACUP
3 Bath Place, Rivington Street, London EC2A 3JR
Cancer Information service, 0800 181199 (freeline)
Cancer Counselling service, 0171 696 9000

British Association for Counselling
1 Regent Place, Rugby CV21 2PJ
01788 578328

British Red Cross Camouflage Service
National Headquarters, 9 Grosvenor Street, London SW1X 7EJ
0171 235 5454

Cancer Care Society
21 Zetland Road, Redland, Bristol BS6 7AH
0117 9427419

Cancer Help Centre
Grove House, Cornwallis Grove, Clifton, Bristol BS8 4PG
0117 9743216

Cancerlink
17 Brittania Street, London WC1X 9JN
0171 833 2451

Cancer Relief Macmillan Fund
Anchor House, 15/19 Britten Street, London Sw3 3TZ
0171 351 7811

Contact A Family
170 Tottenham Court Road, London W1P 0HA
0171 383 3555

Let's Face It
Christine Piff, 14 Fallowfield, Yateley, Surrey, GU17 7LW
01252 879630

APPENDIX: REFERENCES and FURTHER READING

Baker, C. (1992). Factors associated with rehabilitation in head and neck cancer. Cancer Nursing, 15 (6), 395-400.

Baker, C. (1995) A Functional Status Scale for Measuring Quality of Life Outcomes in Head and Neck Cancer Patients. Cancer Nursing, 18 (6), 452-457.

Bedell, J.R. and Lennox, S.S. (1997) (eds) Handbook for Communication and Problem Solving Skills Training. Wiley, New York.

Bjordal, K., Ahlner-Elmquist, M., Tolleson, E., Jensen, A.B., Razari, D., Maler, E.J. and Kaasa, S. (1994) Development of a European Organisation for Research and Treatment of Cancer (EORTC) questionnaire module to be used in quality of life assessments in head and neck cancer patients. EORTC Quality of Life Study Group. Acta Oncologica, 33(8), 879-885.

Bjordal, K., Freng, A., Thorvik, J. and Kaasa, S. (1995) Patient self-reported and clinician rated quality of life in head and neck patients: a cross-sectional study. European Journal of Cancer. Part B, Oral Oncology. 31B(4), 235-241.

Bradbury, E. (1996) Counselling people with disfigurement. British Psychological Society books: Leicester.

Breitbart, W. and Holland, J. (1988) Psychosocial aspects of head and neck cancer. Seminars in Oncology, 151, 61-69

Bryant, B.M. and Trower, P.E. (1974) Social difficulty in a student sample. British Journal of Educational Psychology. 44, 13-21.

Bull, R. and Rumsey, N. (1988) The Social Psychology of Facial Appearance. Springer Verlag: New York..

Bushkin, E. (1995) Excellence in the psychosocial care of the patient with cancer. Oncology Nursing Forum, 22, (3), 537-543.

Carlsson, M., Hamrin, E. (1994) Psychological and psychosocial aspects of breast cancer and breast cancer treatment. A literature review. Cancer Nursing 17 (5), 418-428.

Carr, A. and Harris, D. (1994) The Derriford Scale - short form. Developed by the Disfigurement Research Team: Department of Psychology, University of Plymouth. Unpublished.

Cash, T.F. and Pruzinsky, T. (1990) (eds) Body Images. Development, Deviance and Change. Guilford Press: New York, London.

Clarke, A. (1998) Strategies for managing facial disfigurement. *British Journal of Community Nursing*. 3, 13-16

Clarke, A. (1997b) The design of an information series for people with facial disfigurement. Submitted for publication.

Cobb, S. (1976) Social support as a moderator of life stress. *Psychosomatic Medicine*, 38, (5), 300-314.

Dropkin, M.J., Malgady, R.G., Scott, D.W., Oberst, M.T. and Strong, E. (1983) Scaling of disfigurement and dysfunction in post operative head and neck patients. Head and Neck Surgery, 6, 559-570.

Dropkin, M. (1989). Coping with disfigurement and dysfunction after head and neck cancer surgery: a conceptual framework. Seminars in Oncology Nursing, 5, 213-219.

Edwards, D. (1997) Face to Face. Patient, family and professional perspectives of head and neck cancer care. Kings Fund publishing: London.

Faberow, N.L, Ganzler, S., Cutter, N, Reynolds, C.V. (1971) An eight year survey of hospital suicides. Life Threatening Behaviours, 1, 184-201.

Feber, T (1997) Presentation to 4th National Head and Neck Oncology Conference, Nottingham, April 1997.

Fiegenhaum, W. (1981). A social training program for clients with facial disfigurations: a contribution to the rehabilitation of cancer patients. International Journal of Rehabilitation Research, 4 (4) 501- 509.

Gotay, C.C. and Moore, T.D. (1992) Assessing quality of life in head and neck cancer. Quality of Life Research, 1, 5-17.

Koster, M. and Bergsma, J. (1990). Problems and coping behaviour of facial cancer patients. Social Science Medical, 30 (5), 569-578.

Lansdown, R., Rumsey , N., Bradbury, E., Carr, T. and Partridge, J. (1997) Visibly Different. Coping with Disfigurement. Butterworth: Heinemann, London.

Lazarus, R.S. (1993) Coping theory and research: past, present and future. Psychosomatic Medicine, 55, 234-247.

Macgregor, F. (1990) Facial Disfigurement: problems and management of social interaction and implications for mental health. Aesthetic Plastic Surgery, 14, (4) 249-257.

McGrouther, D.A. (1997) Facial Disfigurement: the last bastion of discrimination. British Medical Journal, 314, 991.

Moss, T. (1997) Individual variation in adjusting to visible differences. In: Lansdown, R., Rumsey, N., Bradbury, E., Carr, T. and Partridge, J. (eds) Visibly Different. Coping with disfigurement. Butterworth Heineman. London.

Partridge, J. (1994). Changing Faces: The Challenge of Facial disfigurement. Penguin Books: London.

Parsons, M. (1997) Presentation to 4th National Head and Neck Oncology Conference, Nottingham, April 1997.

Robinson, E., Rumsey, N. and Partridge, J. (1996). An evaluation of the impact of social interaction skills training for facially disfigured people. British Journal of Plastic Surgery, 1, 49, 281-289.

Robinson, E., Clarke, A. and Cooper, C. (1996) The Psychology of Facial Disfigurement. Changing Faces: London.

Rumsey, N., Bull, R. & Gahagen, D. (1982) The effect of facial disfigurement on the proxemic behaviour of the general public. Journal of Applied Social Psychology, 12 (2), 137-150.

Rumsey, N. (1983) Psychological problems associated with facial disfigurement. Unpublished PhD thesis, North East London Polytechnic.

Rumsey, N. & Bull, R. (1986) The Effects of Facial Disfigurement on Social Interaction. Human Learning, 5, 203-208.

Rumsey, N., Bull. R., & Gahagen. D. (1986). A preliminary study of the effects of social skills training for improving the quality of social interaction for the facially disfigured. Social Behaviour, 1, 143-145.

Rumsey, N. (1997) Historical and anthropological perspectives on appearance. In Lansdown, R., Rumsey, N., Bradbury, E., Carr, T and Partridge, J. (eds) Visibly Different: Butterworth Heineman, London.

Wilson, J. and Myers, J (1998) Self Help Groups. Getting started, keeping going. Published by R.A Wilson, 38 Devon Drive, Sherwood, Nottingham NG5 2EN.

Zigmond, A. and Snaith, R. (1983) The hospital anxiety and depression scale. Acta Psychiatrica Scandinavica, 67, 361-370

Appendix Two:

Research protocol

A SKILLS BASED SOCIAL REHABILITATION PROGRAMME FOR PATIENTS WITH HEAD AND NECK CANCER.

The design, implementation and evaluation of a package for use by head and neck nurses.

INTRODUCTION

About Changing Faces

Changing Faces is a registered charity set up by James Partridge in the aftermath of the publication of his book: Changing Faces: the challenge of Facial Disfigurement in 1990 in which he describes his own experiences in coping with the consequences of severe burns as a teenager.

There are many different causes of visible disfigurement, the most common ones being scarring as a result of burns or road traffic accidents, facial palsies, dermatological conditions (such as acne scarring, vitiligo eczema or psoriasis) as well as those of a congenital nature (e.g. birthmarks, cleft lip and palate), and disfigurement as a consequence of treatment for cancer. Since its launch in 1992, the charity has aimed to provide psychosocial support to visibly disfigured individuals, in the form of counselling, information and advice and uniquely, a *coping skills training package.*

Changing Faces recognises the need to work within a rigorous research framework. Accordingly, the effectiveness of all its interventions are evaluated and if effective, information about our work is disseminated to other professionals by means of publications and professional conferences. We believe that this research ethos is part of a model of best practice for organisations working within the voluntary sector and especially for those attempting to influence clinical management with the health and social services.

Since its launch Changing Faces has secured research funding to:

- evaluate the effectiveness of a social skills training workshop for people with facial disfigurement.
- design and evaluate a resource pack for primary school teachers
- develop an audit methodology to improve the clinical care of visibly disfigured people
- set up and evaluate the effectiveness of the first NHS specialist unit for the management of disfigurement (at Frenchay Hospital, Bristol)

In addition to specific project grants as above, Changing Faces is funded by charitable donations and is supported by the Department of Health. Further details can be found in the Annual report and from the office.

WHY IS THIS PROJECT NEEDED?

Quality of Life in Head and Neck Cancer.

With the technical advances being made in the treatment of head and neck cancer, involving surgery, radiotherapy and chemotherapy, more patients survive the illness. This has led to an awareness of the 'trade-off' between survival, and severe dysfunction and disfigurement, and has generated an enormous amount of research into quality of life and psychosocial issues.(Edwards 1997)

Head and neck cancer is of particular interest because the epidemiology of this relatively rare form of malignancy (approximately 5% of new neoplasms) is changing; well known behavioural risk factors such as cigarette smoking and heavy alcohol use are increasing in younger populations leading to a projected rise in incidence over the next few decades. Even in the absence of risk factors, and perhaps reflecting advances in health care, this is becoming a younger surviving population, for whom the psychosocial consequences of treatment may be overwhelming. Depending on the severity of the disease and the choice of treatment, patients may have severe facial disfigurement, eating difficulties, speech difficulties (often total loss of speech) and problems with pain, loss of shoulder mobility, swallowing, chewing etc.(Baker 1995).

Without exception, research studies with this population highlight the very severe consequences of treatment, sometimes questioning its validity where such severe levels of dysfunction and disfigurement result The majority of studies stress the need for further research on this population and recommend support and counselling. Very few consider strategies for invention; exceptions include Wilson et al (1991) who investigate eating strategies, and Bjordal and Kaasa (1995) who suggest the urgent need for a study to look at the training of coping skills as a possible way forward with this group. Studies have reviewed coping style as a framework for understanding how patients manage the psychosocial problems of treatment, without proposing resulting management strategies and one study (Fiegenbaum et al 1971), has evaluated the effectiveness of coping skills training in the management of disfigurement in this population, but although the outcome was positive, the numbers (8 in the treatment group) prevent generalisation.

The coping skills model is therefore the only one which has received any attention, albeit minute in terms of the extent of the literature.

Potential management of these problems

Since its launch, Changing Faces has been providing social skills training in the form of group workshops as well as on an individual basis, and more recently, it has developed a set of specialised resources including a range of self-help booklets and a video training package. The charity is the first organisation to demonstrate the effectiveness of social skills training for facially disfigured people (Robinson 1996) The research shows significant decreases in anxiety, social anxiety and significant increases in confidence amongst those taking part in training workshops. (in fact 15 of these had had facial cancer).

Although disfigurement is only one of the problems for the head and neck cancer group, it is very commonly the social consequences of other dysfunctions such as eating difficulties and speech production which patients describe as distressing. Thus eating and speaking in front of others cause social anxiety and embarrassment, and a pattern of social avoidance results which very closely matches the pattern we see in the Changing Faces population of disfigured adults.

Clarke (1997) has proposed that this model of training in social interaction skills is therefore a valid one for planning an intervention strategy in the rehabilitation of people with head and neck cancer.

Current NHS provision for patients with Head and Neck cancer

Perhaps because of the interest in quality of life issues, the current provision of care for these patients is improving. The Macmillan fund have an active program of funding 'head and neck nurses', and the provision of a specialist nurse is seen as a priority by many surgeons. However, the skills background is mixed; some nurses have done ENT courses, some have done Plastic surgery courses. For all of them, the medical/surgical model of intervention predominates in their training. They may be very skilled in providing training in management of a tracheostomy, but unskilled in preparing patients for the reactions of others to laryngeal speech, they may be able to advise on the preparation of food, but not on how to mange eating in front of other people; they may be able to advise on pain management, but not about walking down the street and coping with staring, name calling and questions.

Changing Faces receives many requests from these nurses who want to secure further training and have access to our resources.

In summary, there is tremendous scope for extending the skill set of the people in post in the NHS to more closely match the needs of the population that they are caring for.

PROJECT AIMS

The aims of this project are:

- to identify the existing skills and skill deficits in head and neck nurses
- to design an intervention package for use by head and neck nurses which extends their skills with particular reference to the social rehabilitation of head and neck cancer patients
- to pilot the package by training a small number of nurses to use it
- to measure the downward transfer of skill from Changing Faces, to the nurses and then on to the patients.
- to make recommendations about the value of social interaction skills training as a conceptual framework for the rehabilitation of head and neck cancer patients.
- to make recommendations about the value of training nurses to use the Changing Faces package for head and neck cancer patients , and proposals for a full scale study
- to make recommendations about extending both the training model and the package for use with other groups of patients.

PROJECT METHODOLGY

Subjects

Nurses skill level has been evaluated using a comprehensive questionnaire distributed to all nurses who are members of the British Association of Head and Neck Nurses, and to all nurses on the Changing Faces database.

Nurses interested in participating in the study have been recruited. (N= 10 for the study, and 10 for the control group)

All nurses will be asked to agree to complete questionnaires sent to them by post, and to obtain data from ten patients using standardised quality of life measures, and self report measures designed for the study.

Nurses in the experimental group will be asked to agree to attend a training day, and to undertake to use the training package with at least ten patients, collecting data from them pre and post intervention.

Ethical approval for the study has been obtained from City University and will be applied for at each participating nurse's health authority. All patients will be given written information about the study and asked for written consent. (See attachments)

Design

A multiple baseline design will be used to measure change in skill in the nursing population. Since the study is training nurses to provide social interaction skills, there should be no change in their perceived ability to provide pain management or care of a tracheostomy. A comparison can therefore be made between those skills targeted and those not.

In addition, data will be collected from a control group of nurses.

Patients will be asked to complete self report questionnaires before and after their rehabilitation programme.

Self report measures include standardised Quality of Life measures developed for head and neck cancer patients. Permission to use the EORTC head and neck module is being sort, and other semistructured questionnaires designed for the study will measure perceived level of skill in parallel with that designed for the nurses.

WHAT OUTCOMES ARE ANTICIPATED?

Academic

- A conceptual framework for understanding the consequences of head and neck cancer in terms of social impact will be supported

For nurses

- Skills deficits in head and neck nurses will be demonstrated and a training package designed which will allow them to meet the needs of their patients more fully

For patients

- Patients will receive training in how to manage social interaction problems which will improve their coping skills and quality of life

For Changing Faces

- A model for training health professionals working with other patient groups will have been evaluated.

PROJECT STAFFING

As a research based charity, Changing Faces has the necessary expertise and knowledge to undertake this programme of work.

The research will be carried out by:

Alex Clarke BSc, MSc, AFBPS, SRN, Chartered Clinical Psychologist, Clinical Coordinator at Changing Faces, London.

This research forms part of a Doctor of Clinical Psychology training, at City University, London, supervised by Professor Robert Bor

TIMESCALE

The project is planned to start in July 1997 and will take two years as follows:

July 1997 98	design training manual
July 1998	training session with nurses
July - September	obtain all ethical consent from participating authorities
October - February	data collection from and by nurses
February - April	analysis and writing up results

Appendix Three

Patient information and consent forms

Questionnaires and rating scales

(Nurses follow up questionnaire, completed in addition to skills rating scale)

PLEASE COMPLETE THE FOLLOWING QUESTIONS AS FULLY AS YOU CAN.

The first set of questions relates to ease of use.

1. Overall, how do you rate this resource pack on the following criteria?

Please tick in appropriate box

	poor	**average**	**good**	**excellent**
readability				
ease of understanding				
informativeness				
ease of use				
comprehensiveness				
practical usefulness				

2. Have you any other comments about the presentation and layout of the pack?

……………………………………………………………………………………

……………………………………………………………………………………

……………………………………………………………………………………

The second set of questions relate to relevance for the head and neck cancer population:

3 How helpful is this coping skills model for rehabilitation in this population?

very helpful *quite helpful* *not very helpful* *very unhelpful*

4 Is the inclusion of relatives in the exercises and examples helpful?

very helpful *quite helpful* *not very helpful* *very unhelpful*

5 Does the pack have any unnecessary sections?
Yes/No

(If yes, please give
details:)…………………………………………………………………

…………………………………………………………………………

6 Does the pack have any obvious omissions that could be added?
Yes/No

(If yes, please give
details:)………………………………………………………………….

…………………………………………………………………………

7 Is there any section of the pack that you found particularly helpful or unhelpful?
Yes/No

(Please give
details:)………………………………………………………………………….

………………………………………………………………………………………

The third set of questions relate to your own skills

8 Has the pack added to your basic skill set in dealing with patients' social rehabilitation?

not at all *a little* *quite a lot* *very much*

9 Has the pack increased the variety of ideas and strategies that you can use to help patients manage particular problems?

very much *quite a lot* *a little* *not at all*

10 Does the pack enable you to *deliver* rehabilitation strategies effectively?

not at all *a little* *quite a lot* *very much*

11 Has the pack increased your confidence about dealing with social rehabilitation issues?

not at all *a little* *quite a lot* *very much*

12 Has the pack encouraged you to involve relatives more in rehabilitation?

not at all *a little* *quite a lot* *very much*

13 Has the pack helped you to use existing resources?

very much *quite a lot* *a little* *not at all*

14 Has the pack influenced the timing of your intervention with patients?

very much *quite a lot* *a little* *not at all*

15 How do you think you are likely to use the pack with your patients? (Please tick as many as applicable)

Not at all

As an information resource for myself

To support individual sessions

To run support groups

To provide written/video information for patients

15 Do you think that the pack should be made more widely available?

Definitely *yes, with amendments* *don't know* *Not at all*

Please use the space overleaf to add any of your own comments about the pack together with any other suggestions for improving it.

THANK YOU VERY MUCH FOR COMPLETING THESE QUESTIONNAIRES.

PATIENT INFORMATION SHEET

SOCIAL REHABILITATION AFTER HEAD AND NECK SURGERY

You are invited to take part in a research study. Before you decide whether or not you wish to take part in is important for you to understand why the study is being done and what it will involve if you agree to take part. Please read the following information carefully. Discuss it with your friends and relatives if you wish. Ask us if there is anything you don't understand or if you would like more information. You will be given as much time as you want to make a decision.

Consumers for Ethics in Research (CERES) publish a leaflet called Medical Research and You. This leaflet gives more information about medical research and can be obtained from the nurse inviting you to take part.

What is the purpose of the study?

Doctors and other health professionals are very interested in how head and neck surgery affects people's day to day lives. It has been suggested that people would like more support when they go home, especially in the form of written information and practical advice about how to manage any difficulties that they have.

The charity Changing Faces has produced some new materials, booklets etc., to help the team looking after you to provide this support. We would like to know whether or not you find this practical support and written information helpful.

Why have I been chosen?

Everyone who has recently undergone head and neck surgery is being asked if they would like to participate in this research.

Who is organising the study?

The study is being run in eight different centres, by the charity, Changing Faces.

What will happen if I take part?

If you agree to take part, the Head and Neck nurse will talk to you about any concerns you have after surgery, particularly those that involve mixing with other people, e.g.: changes in your voice, your appearance, any eating difficulties etc. She will ask you to complete a questionnaire before she offers you written information, or the chance to take part in a support group, and again, a few weeks later.

Do I have to take part?

You do not have to take part in this study. If you would prefer not to, you do not have to give a reason. Your doctor will not be upset and your treatment will not be affected. You will receive the usual treatment for patients following Head and Neck surgery. You may also withdraw from the study at any time.

Are there any benefits or risks in taking part?

Everyone who attends this clinic is offered support and information. There are therefore no direct benefits or risks to you in taking part in the research study. However, your views on whether this kind of support is helpful, is very valuable in helping us to know what kind of help to offer other people.

Who will see my records and know about my taking part?

No-one apart from the team looking after you has access to your records, so any information collected about you will be confidential. The questionnaires that you complete will be numbered, so all information about you that leaves the hospital will be anonymous, and no-one will be able to recognise you from it.

Will anybody involved in the study be paid?

Changing Faces is paying for this research, but none of the nurses or doctors are receiving any money.

What if I have any concerns?

If you have any problems, concerns, complaints or other questions about this study, you should contact the Head and Neck nurse first, (name, address and telephone number). Alternatively, you may contact (name of complaints department and name and address of hospital, on telephone no.)

CONSENT FORM

SOCIAL REHABILIATION AFTER HEAD AND NECK SURGERY

(space for patient label)

To be completed by the patient
**delete as necessary*

1 Have you understood the attached information sheet about this study?
*YES/NO

2 Have you had the opportunity to ask questions and discuss this study?
*YES/NO

3 Have you received satisfactory answers to all your questions?
*YES/NO

4 Have you received enough information about this study?
*YES/NO

5 Do you understand that you do not have to take part in this study, that you do not need to give a reason, and that withdrawal from the study will not affect your future medical care?
*YES/NO

6 Do you agree to take part in this study?
*YES/NO

Print name...

Signature of patient....................................

The explanation of this study has been given by:

Print name....................................

Signature of Research Team member

Date:.........................

Patient identification number/code..........................

PATIENT INTERVIEW SCHEDULE

Section A: Demographic Details

A1. **Identity no::**.................................. A2. **Male(1)**...... **Female(2)**......

A3. **Age:** ......years

A4 **Living alone(1)**.................. **Living with a partner(2)**..........

A5. **Ethnic origin:**

White(1).....................	Black-Caribbean(2).....................
Black African(3)............	Black other(4) *please describe*..........
Indian(5).....................	Pakistani(6)................................
Bangladeshi(7)..............	Chinese(8)................................

Any other ethnic group*(please describe)*...

A6. **Currently working** **Yes(1)**......... **No(2)**..........

A7 **Occupation**..
(to be coded according to census classification)

A8 **If working,** **full-time(1)**.......... **Or part-time(2)**..........

A9 **If unemployed**

(a) **Has s/he always been?** **Yes(1)**.......... **No(2)**..............

(b) **When did s/he last work?**

- less than 6 months ago(1)........................
- more than 6 but less than 12 months ago(2).........
- more than 1 year but less than 3 years ago(3)........
- more than 3 years ago(4)..............

(c **previous employment**..
(to be coded according to census classification)

A10 **If retired:**

(a) **How long has s/he been retired?**

- Less than 6 months(1)................
- more than 6 but less than 12 months ago(2).........
- more than a year but less than 3 years ago(3).........
- more than 3 years ago(4)........................

(b) **What was his/her last job?**..................................
(to be coded according to census classification)

Section B: Medical details

With regard to (insert patients identifying code)..............................

B1 **Diagnosis?**

Oral cavity(1)....... pharynx(2)....... larynx(3).......

B2 **Surgical stage?**

1(1)........ 11(2)......... 111(3)........1V(4)...........

B3 **Treatment modality?**

surgery(1)....... radiotherapy(2)......... Chemotherapy(3).........

please give any further relevant information ....

....

....

...

B4 **How long ago did treatment finish?**

(a) less than 6 months ago(1)......................
(b) more than 6 but less than 12 months ago(2).............
(c) more than 1 but less than 3 years ago(3)......................
(d) more than 3 years ago(4)....................................

How would you rate the following?

B4 **Dysfunction, using Dropkin scale** (please underline)

order **1** loss of smell

2 unilateral hearing loss

3 impaired mastication

4 impaired speech

5 unilateral loss of vision

6 impaired control of salivary secretions

7 impaired deglutition

8 aphonia

B5 **Disfigurement using Dropkin scale (please underline)**

order **1** radical neck dissection

2 cheek resection with forehead flap repair

3 total parotidectomy with facial nerve sacrifice

4 total laryngectomy

5 bilateral radical neck resection

6 orbital exenteration

7 hemimandibulectomy and radical neck dissection

8 nasal amputation

9 anterior partial mandibulectomy

10 segmental mandibulectomy and radical neck dissection

11 orbital exenteration and radical maxillectomy

B6 **With regard to smoking, would you describe his/her habit as:**

(a) **pre-operatively** *(figures are per day)*

None(1)……… **5 or less** (2)……..**6-10**(3)……**10-20**(4)…..**21+**(5)……..

(b) **post-operatively**

None(1)……… **5 or less**(2)…….. **6-10**(3)…….**10-20**(4)…. **21+**(5)……..

B7 **With regard to drinking, would you describe his/her habit as:**

(a) **pre-operatively:** *(figures in **bold** are in units per day)*

None(1)……. **1**(2)……. **2-3**(3)……. **4+**(4)…….

(b) **post-operatively:**

None(1)…….. **1** (2)…… **2-3**(3)……… **4+**(4)…..

(front sheet for standardised questionnaires)

PRELIMINARY QUESTIONNAIRE

We would be grateful if you would complete the following questionnaire.

Do not spend too long on any one question.

If you have difficulty with any of the questions, or if any of the questions raise concerns that are worrying you, please talk to the nurse about them.

QLQ-C30 (version 3.0)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

	Not at All	A little	Quite a bit	Very much
1. Do you have any trouble doing strenuous activities, like carrying a heavy bag or suitcase?	1	2	3	4
2. Do you have any trouble taking a **long** walk?	1	2	3	4
3. Do you have any trouble taking a **short** walk outside of the house?	1	2	3	4
4. Do you have to stay in bed or a chair for most of the day?	1	2	3	4
5. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4

During the past week:

6. Were you limited in doing either your work or other daily activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10.Did you need to rest?	1	2	3	4
11 Have you had trouble sleeping?	1	2	3	4
12 Have you felt weak?	1	2	3	4
13 Have you lacked appetite?	1	2	3	4
14 Have you felt nauseated?	1	2	3	4
15 Have you vomited?	1	2	3	4
16Have you been constipated?	1	2	3	4
17 have you had diarrhoea?	1	2	3	4

	Not at all	A little	Quite a bit	Very much
18 Were you tired?	1	2	3	4
19 Did pain interfere with your daily activities?	1	2	3	4
20 Have you had difficulty in concentrating on things, like reading the newspaper or watching television?	1	2	3	4
21 Did you feel tense?	1	2	3	4
22 Did you worry?	1	2	3	4
23 Did you feel irritable?	1	2	3	4
24 Did you feel depressed?	1	2	3	4
25 Have you had difficulty remembering things?	1	2	3	4
26 Has your physical condition or medical treatment interfered with your **family** life?	1	2	3	4
27 Has your physical condition or medical treatment interfered with your **social** activities?	1	2	3	4
28 Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you

29 How would you rate your overall health during the last week?

1	2	3	4	5	6	7
very poor						Excellent

30 How would you rate your overall **quality of life** during the past year?

1	2	3	4	5	6	7
very poor						Excellent

ENGLUSH

EORTC QLQ - H&N35

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems during the past week. Please answer by circling the number that best applies to you.

During the past week:	**Not at all**	**A little**	**Quite a bit**	**Very much**
31. Have you had pain in your mouth?	1	2	3	4
32. Have you had pain in your jaw?	1	2	3	4
33. Have you had soreness in your mouth?	1	2	3	4
34. Have you had a painful throat?	1	2	3	4
35. Have you had problems swallowing liquids?	1	2	3	4
36. Have you had problems swallowing pureed food?	1	2	3	4
37. Have you had problems swallowing solid food?	1	2	3	4
38. Have you choked when swallowing?	1	2	3	4
39. Have you had problems with your teeth?	1	2	3	4
40. Have you had problems opening your mouth wide?	1	2	3	4
41. Have you had a dry mouth?	1	2	3	4
42. Have you had sticky saliva?	1	2	3	4
43. Have you had problems with your sense of smell?	1	2	3	4
44. Have you had problems with your sense of taste?	1	2	3	4
45. Have you coughed?	1	2	3	4
46. Have you been hoarse?	1	2	3	4
47. Have you felt ill?	1	2	3	4
48. Has your appearance bothered you?	1	2	3	4

During the past week:	Not at all	A little	Quite a bit	Very much
49. Have you had trouble eating ?	1	2	3	4
50. Have you had trouble eating in front of your family?	1	2	3	4
51. Have you had trouble eating in front of other people?	1	2	3	4
52. Have you had trouble enjoying your meals?	1	2	3	4
53. Have you had trouble talking to other people?	1	2	3	4
54. Have you had trouble talking on the telephone?	1	2	3	4
55. Have you had trouble having social contact with your family?	1	2	3	4
56. Have you had trouble having social contact with friends?	1	2	3	4
57. Have you had trouble going out in public?	1	2	3	4
58. Have you had trouble having physical contact with family or friends?	1	2	3	4
59. Have you felt less interest in sex?	1	2	3	4
60. Have you felt less sexual enjoyment?	1	2	3	4

During the past week:	No	Yes
61. Have you used pain-killers?	1	2
62. Have you taken any nutritional supplements (excluding vitamins)?	1	2
63. Have you used a feeding tube?	1	2
64. Have you lost weight?	1	2
65. Have you gained weight?	1	2

How would you rate your skills in managing the following?

	need more advice	*adequate*	*good*	*very good*
your pain relief	☐	☐	☐	☐
coping with the change in your appearance	☐	☐	☐	☐
coping with others staring	☐	☐	☐	☐
dealing with comments and questions from others	☐	☐	☐	☐
management of your tracheostomy (if relevant)	☐	☐	☐	☐
communication strategies (talking to other people)	☐	☐	☐	☐
using the telephone	☐	☐	☐	☐
managing the impact of altered speech (if relevant)	☐	☐	☐	☐
taking the initiative in social situations	☐	☐	☐	☐
choice and preparation of food	☐	☐	☐	☐
strategies for eating out	☐	☐	☐	☐
resuming social activities with family and friends	☐	☐	☐	☐
developing confidence in social situations, e.g.: public transport, supermarket, large groups of people	☐	☐	☐	☐
changes in close relationships e.g.: sex life	☐	☐	☐	☐
resuming everyday activities, e.g.: housework	☐	☐	☐	☐
preparing to return to work	☐	☐	☐	☐
changing smoking, drinking habits	☐	☐	☐	☐

INSTRUCTIONS

Below you will find listed 30 situations you might encounter, which some people have said they find difficult. Please indicate how much difficulty, if any, you have in each of these situations using the scale below.

If some of these situations are ones in which you have never found yourself, please imagine how you would feel if you did.

For each situation select the choice of difficulty which most closely fits how you feel and write the number of your choice in the box provided.

No difficulty	Slight difficulty	Moderate difficulty	Great difficulty	Avoidance if possible
0	1	2	3	4

1	Walking down the street	
2	Going into shops	
3	Going on public transport	
4	Going into pubs	
5	Going to parties	
6	Mixing with people at work	
7	Making friends of your own age	
8	Going out with someone of the opposite sex	
9	Being with a group of the same sex and roughly the same age as you	
10	Being with a group containing both men and women of roughly the same age as you	
11	Being with a group of the opposite sex of roughly the same age as you	
12	Entertaining people in your home, lodgings etc..	
13	Going into restaurants or cafes	

14	Going to dances, dance halls or discotheques	
15	Being with older people	
16	Being with younger people	
17	Going into a room full of people	
18	Meeting strangers	
19	Being with people you don't know very well	
20	Being with friends	
21	Approaching others - making the first move in starting up a friendship	
22	Making ordinary decisions affecting others (eg what to do together in the evening)	
23	Being with only one other person rather than a group	
24	Getting to know people in depth	
25	Taking the initiative in keeping a conversation going	
26	Looking at people directly in the eye	
27	Disagreeing with what other people are saying and putting forward your own views	
28	People standing or sitting very close to you	
29	Talking about yourself and your feelings in a conversation	
30	People looking at you	

Instructions: The following questions and statements are concerned with the way you feel or act. They are all simple. Please tick the answer that applies to you. If the item does not apply to you at all, tick the N/A (Not Applicable) option. Don't spend long on any one question.

1. **How confident do you feel?**

   Not at all .... Slightly .... Moderately .... Extremely ....

2. **How distressed do you get when you see yourself in the mirror/window?**

   Extremely...... Moderately.... Slightly .... Not at all Distressed ....

3. **My self-consciousness makes me irritable at home:**

   N/A .... Never/almost never .... Sometimes .... Often .... Almost always ....

4. **How hurt do you feel?**

   Extremely .... Moderately .... Slightly .... Not at all ....

5. **At present my self-consciousness has an adverse effect on my work:**

   Almost always .... Often .... Sometimes .... Never/almost never .... N/A ....

6. **How distressed do you get when you go to the beach?**

   N/A .... Not at all .... Slightly .... Moderately .... Extremely ....

7. **Other people mis-judge me because of my feature:**

   Almost always .... Often .... Sometimes .... Never/almost never ...... N/A ....

8. **How feminine/masculine do you feel?**

   Not at all .... Slightly .... Moderately .... Extremely ....

9. **I am self -conscious of my feature:**

   N/A .... Never/ almost never .... Sometimes .... Often .... Almost always ....

10. **How irritable do you feel?**

    Not at all .... Slightly .... Moderately .... Extremely ....

11. **I avoid getting my hair wet:**

    Almost always .... Often .... Sometimes.... Never/almost never ....

12. **I adopt certain gestures (e.g. folding my arms in front of other people, covering my mouth with my hand):**

    Never/almost never .... Sometimes .... Often .... Almost always ....

13. **I avoid communal changing rooms:**

    Almost always .... Often .... Sometimes....Never/almost never ..... N/A .....

14. **How distressed do you get by shopping in department stores/supermarkets?**

N/A .... Not at all .... Slightly .... Moderately .... Extremely .....

15. **How rejected do you feel?**

Not at all .... Slightly .... Moderately .... Extremely ....

16. **I avoid undressing in front of my partner:**

N/A.... Never/almost never .... Sometimes .... Often .... Almost always ....

17. **How distressed do you get while playing sports/games?**

Extremely .... Moderately .... Slightly .... Not at all .... N/A ....

18. **I close into my shell:**

Almost always .... Often .... Sometimes.... Never/almost never ....

19. **How distressed are you by being unable to wear your favourite clothes?**

Extremely .... Moderately .... Slightly .... Not at all .... N/A ....

20. **How distressed do you get when going to social events?**

N/A.... Not at all ....Slightly ...... Moderately .... Extremely ....

21. **How normal do you feel?**

Not at all .... Slightly .... Moderately .... Extremely ....

22. **At present my self-consciousness has an adverse effect on my sex life:**

Almost always .... Often .... Sometimes.... Never/almost never .... N/A ....

23. **I avoid going out of the house:**

Almost always .... Often .... Sometimes.... Never/almost never ....

24. **How distressed do you get when other people make remarks about your feature?**

N/A.... Not at all ...... Moderately .... A fair amount .... Extremely ....

25. **I avoid going to pubs/restaurants:**

Almost always .... Often .... Sometimes....Never/almost never .... N/A ....

26. **At present I try to avoid going to work/school/college:**

N/A ...... Never/almost never ..... Sometimes ..... Often ..... Almost always ......

27. **My feature causes me physical pain/discomfort: :**

N/A ...... Never/almost never .... Sometimes .... Often .... Almost always .....

28. **My feature limits my physical ability to do the things I want to do:**

Almost always .... Often .... Sometimes....Never/ almost never .... N/A ......

How do you feel now?

Read each item and place a firm tick in the box opposite the reply which comes closest to how you have been feeling in the last week.

I feel tense or 'wound up':

- Most of the time ☐
- A lot of the time ☐
- From time to time, occasionally ☐
- Not at all ☐

I still enjoy the things I used to enjoy:

- Definitely as much ☐
- Not quite so much ☐
- Only a little ☐
- Hardly at all ☐

I get a sort of frightened feeling as if something awful is about to happen:

- Very definitely and quite badly ☐
- Yes, but not too badly ☐
- A little, but it doesn't worry me ☐
- Not at all ☐

I can laugh and see the funny side of things:

- Asmuch as I always could ☐
- Not quite so much now ☐
- Definitely not so much now ☐
- Not at all ☐

Worrying thoughts go through my mind:

- A great deal of the time ☐
- A lot of the time ☐
- From time to time but not too often ☐
- Only occasionally ☐

I feel cheerful:

- Not at all ☐
- Not often ☐
- Sometimes ☐
- Most of the time ☐

I can sit at ease and feel relaxed:

- Definitely ☐
- Usually ☐
- Not often ☐
- Not at all ☐

I feel as if I am slowed down:

- Nearly all the time ☐
- Very often ☐
- Sometimes ☐
- Not at all ☐

I get a sort of frightened feeling like "butterflies" in the stomach:

- Not at all ☐
- Occasionally ☐
- Quite often ☐
- Very often ☐

I have lost interest in my appearance:

- Definitely ☐
- I don't take as much care as I should ☐
- I may not take quite as much care ☐
- I take just as much care as ever ☐

I feel restless as if I have to be on the move:

- Very much indeed ☐
- Quite a lot ☐
- Not very much ☐
- Not at all ☐

I look forward with enjoyment to things:

- As much as ever I did ☐
- Rather less than I used to ☐
- Definitely less than I used to ☐
- Hardly at all ☐

I get sudden feelings of panic:

- Very often indeed ☐
- Quite often ☐
- Not very often ☐
- Not at all ☐

I can enjoy a good book or radio or TV programme:

- Often ☐
- Sometimes ☐
- Not often ☐
- Very seldom ☐

Thank you for taking the time to complete this questionnaire. If you have any further comments that you would like to make, please feel free to use this page to do so.

NAME:..............................

FOLLOW UP QUESTIONNAIRE

How have you used the social rehabilitation resources with this patient?

a) via a support group

number of sessions attended..................................

number of sessions d.n.a.......................................

with partner? yes/no

b) through individual sessions

number of sessions attended....................................

number of sessions d.n.a...

with partner? yes/no

c) by providing information

cancer booklet	**yes/no**
staring booklet	**yes/no**
making the change booklet	**yes/no**
eye booklet	**yes/no**
graded handouts	**yes/no**
sex and intimacy handout	**yes/no**
REACH OUT video	**yes/no**

FOLLOW UP QUESTIONNAIRE

We would be grateful if you would complete the following questionnaire.

Do not spend too long on any one question.

If you have difficulty with any of the questions, please ask for advice.

SECTION A: Please complete this section if you received written information,

1 With regard to managing social situations, have you found the written information easy or difficult to understand?
(please circle)

(a)	(b)	©	(d)
very easy	quite easy	difficult	verydifficult

2 Has the information been helpful or unhelpful?
(please circle)

(a)	(b)	©	(d)
Very helpful	quite helpful	not helpful	very unhelpful

If you answered (a) or (b) above, please tell us what information was most helpful

....

....

If you answered © or (d) above, please tell us why this information was not helpful, or how you think it could be improved.

....

....

3 How effective was the information in helping you to manage any problems?

(a)	(b)	©	(d)
Very helpful	quite helpful	not helpful	very unhelpful

If you answered (a) or (b), how did the information help?

SECTION B: Please complete this section if you attended a support group

1. Did you find the sessions helpful or unhelpful?: *(please circle)*

(a)	(b)	©	(d)
very helpful	quite helpful	not helpful	very unhelpful

If you answered (a) or (b) above, in what way did the sessions help you?

....

....

If you answered © or (d) above, please tell us why the sessions were unhelpful, and how you think they could be improved.

....

....

2. Have you used any of the practical ideas to manage day to day social situations?

(a)	(b)	©
Many of them	Some of them	None of them

If you answered (a) or (b) above, please tell us which ideas you have used at home, and whether they were effective.

....

....

If you answered (d) above, please tell us why you have not used them.

....

SECTION C For ALL to complete

1. **Have you found it helpful or unhelpful to have advice about managing social situations?**

(a)	**(b)**	**©**	**(d)**
Very helpful	quite helpful	not helpful	very unhelpful

2 Do you think it is helpful or unhelpful for relatives to be involved in managing social situations?

(a)	(b)	©	(d)
Very helpful	quite helpful	not helpful	very unhelpful

3 Please use the space below for any other comments:

THANK YOU VERY MUCH FOR COMPLETING THIS QUESTIONNAIRE