

Psycho-social
REHABILITATION
in burn care

Why Me?
What will
I LOOK LIKE?
When will
I FEEL better?
WHO can I TALK to?
how will I COPE?

Introduction **How to use this training – trainer’s notes**

The National Burn Care Review in 2001 produced a consensus report identifying that psycho-social support provided for burns patients was a major weakness in UK burns services. A psycho-social working party, set up in 2003, culminated in producing a revised set of standards in 2008 aiming to address this important area of care. The overall aim of these revised standards is that all staff are able to recognise distress signals and that the relevant staff are fully equipped, trained and resourced to deliver the appropriate tools, strategies, psychological support, information and advice responding to patients’ needs, therefore empowering patients and their families.

This training package, commissioned by the London and South East Burns Network, is designed to contribute towards achieving these standards and ultimately improve the delivery of psycho-social care within burns services and patient outcome.

This training package has been piloted in the burns services of the London and South East Burns Network and evaluated by the Centre for Appearance Research (CAR) with successful results.

Training all staff in a burns service is a challenge as team members will have different levels of experience, educational level and knowledge. Throughout this pack there are guidelines provided relating to the use of the package which will help you use the training resource effectively.

Allocating staff to the appropriate training tier

Staff should be allocated to one of three tiers:

Tier 1: Mainly non-clinical staff who do not have direct clinical contact with patients (receptionist, porter etc)

Tier 2: Majority of clinical staff who have clinical contact with patients (nurse, occupational therapist etc)

Tier 3: Staff whose job role involves providing specialist psycho-social care (including spiritual care) or staff who have particular skills, experience or responsibility for psycho-social care (assistant psychologist, chaplain etc).

To assist you in allocating staff to the appropriate tier a ‘Tier Allocation Questionnaire’ is provided. This questionnaire is multiple-choice and staff should answer six simple questions about the degree to which they have contact with patients in their job role and the nature of this contact. Adding up their answers will provide them with a ‘Tier Suggestion’. The results of the questionnaire should be used in conjunction with a manager’s opinion to ensure all staff receive the appropriate training for their job role.

The structure of the training package

There are five modules. We suggest modules are completed as follows:

	Module 1	Module 2	Module 3	Module 4	Module 5
Tier 1 staff	✓	✓			
Tier 2 staff	✓	✓	✓	✓	
Tier 3 staff	✓	✓	✓	✓	✓

It is suggested that each module will take approximately one hour to complete. Tier 1 staff undertake two hours of training; tier 2 staff undertake four hours of training and it should take tier 3 staff five hours to complete the training package.

Note – modules 1 and 2 are very basic for tier 2 and 3 staff, and these two modules will probably be completed in less than two hours. This will allow the tier 2 and 3 learner to spend longer on modules 3 and 4.

The aims of the modules

Module 1: To understand the importance of psycho-social care and to review the member of staff's role in the provision of this support for burns patients;

Module 2: To recognise and show an understanding of a patient's physical, psychological and social needs;

Module 3: To continue to explore the impact of burn injuries on the patient as well as the patient's family, friends and significant others;

Module 4: To investigate the factors that predict good psycho-social outcome and the role of the health care professional in facilitating this;

Module 5: To explore other factors that predict or hinder psycho-social outcome and to discuss the role of psychological therapies, and other providers offering patient and family support.

How to conduct the training

The training has been developed to offer maximum flexibility of delivery. It can be offered to a multi-disciplinary or uni-disciplinary group, and modules 1 and 2 can be covered as a cross tier group if thought to be appropriate.

Suggestions for delivery:

- *During the resource pilot, the learning experiences and benefits achieved by those learners undertaking the training as a group were found to be significantly greater and more positive than the gains from those undertaking the training individually (self-directed).*
- *It is therefore recommended that where possible the training is offered in multi-disciplinary group format. This offers more opportunity for reflection and discussion, and learners will gain maximum benefit from the exercises in this way.*
- *If learners are given a booklet to complete by themselves then it is recommended that a mentor or a trainer supports them to supplement their self-directed learning.*
- *Tier 1 learners may not be used to self-directed study and therefore consideration should be given as to how the training is conducted and followed up with this group of staff.*

What you will find in your trainer package

- *One copy of the trainer manuals for tiers 1, 2 and 3; all trainer manuals contain recommended learner responses and additional 'points for discussion';*
- *Copies of the student manuals for each tier which can be photocopied;*
- *A CD with PowerPoint slides which can be used to supplement the student booklets. You are able to put these slides onto your own organisation's PowerPoint template;*
- *The CD also contains electronic copies of all the manuals, from which you are able to print the whole manual, or selected sections;*
- *A DVD with video clips to supplement the training.*

Using the package effectively

Each module is designed to be worked through systematically. The training package is designed to meet a range of learning styles and therefore includes a variety of materials.

Throughout the course the learner will have the opportunity to participate in reflection, a discussion of case studies and will be able to consolidate theoretical information. References are provided throughout the modules to provide further information on the topics covered.

Throughout the manuals you will see the following symbols:



Key information

This section will provide a discussion of some of the key theoretical information to ensure you cover the main aims and objectives of the module. Some of the large sections of text are supported by trainer PowerPoint slides in your pack.



Case study

This section introduces a patient scenario. This will usually be followed by some questions or a structured discussion on the issues raised. You may want to replace some of these with a discussion of current patients on your ward.



Task

The learner will be asked to answer a question on a topic relevant to the module and the key information given. This could be completed in groups or individually.



Reflection

This provides a relevant topic and the learner will be asked to reflect on previous patients or scenarios. The learner should be encouraged to complete these sections in their own time and discuss with you if they need to.



Further reading

Further information such as journal articles, books and web links are here.

Module 1 What is psycho-social care?

Aim: to understand the importance of psycho-social care and to review your role in the provision of this support for burns patients.

Tier 2 and 3 learners may find these first couple of modules easy. They may choose to work through them in their own time, or discuss in groups. Tier 2 and 3 learners may wish to spend less time on modules 1 and 2 to allow for more time on modules 3 and 4. The case studies can be changed for tier 3 learners to make them more detailed, or you may wish to change the questions asked to require more of the learner. They should be encouraged to fully justify their answers throughout.

To understand the importance of psycho-social care in addition to physical care for burns patients, it is important to first look at what we mean by psycho-social care. This module aims to explore this concept. Below you will find a case study of a potential patient who is admitted to the burns service. Think about your role in this patient’s care provision:



Case study 1 – Kev

Kev is a 21 year old male who has been admitted to your ward with burns causing significant injuries to his hands and arms.



Task

Discuss and write down your role in Kev’s care.

Here we would like to see the learner accurately describe their job role as applied to Kev’s care. They may choose to give an example of a daily work pattern or list all the activities they may be involved with. Tier 2 and 3 learners may also choose to detail common barriers when working with patients and barriers to care.

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Task

Who else is involved in Kev's care and the care of his family and friends? You may want to draw a diagram of your service, or write down the other professionals or members of the multi-disciplinary team with whom you work on a day-to-day basis.

They should show a comprehensive awareness of other professionals involved in Kev's care. This should include the main medical staff and the wider multi-disciplinary team such as physiotherapists, health care assistants and occupational therapists (as appropriate). They should also be able to identify other staff as being important in Kev's care such as volunteers and chaplains. A clear and comprehensive understanding of the psychological therapy services provided in your hospital should also be included.

The learner may also want to detail wider services such as outside agencies and voluntary groups, patient support networks etc.

What is psycho-social care? (PowerPoint 1)



Key information

Psycho-social care can include supporting patients with their emotions, feelings and behaviours and in addition, helping them to communicate with others. Many patients also require support and reassurance with other areas of their personal and social life; this may also include meeting the needs of their family and friends.

Burns injuries, especially if they are severe, can be a life changing experience and may involve a long stay in hospital and further treatment after discharge. Patients will often need help and specialist support to develop new strategies to cope with the effects of their injuries. This can include helping them with the effects of trauma, a changed appearance or scarring, and adapting to physical limitations. Without such support people may develop long term psychological and social difficulties, such as becoming withdrawn from society, struggling in school and work and not feeling able to live a full and happy life. The term 'quality of life' is used to reflect how much a person's physical, psychological and social needs contribute to their ability to enjoy their life. The more difficulties they have, the lower their quality of life is likely to be. Meeting a patient's needs and helping them to help themselves will improve their quality of life. For the purpose of this manual we will use the acronym SPEMS to describe the areas of a patient's life where they may need psycho-social support.

SPEMS



ocial

Interacting and successfully communicating with family, friends, colleagues and other members of society. Participating in daily life activities and social occasions, such as going to the supermarket, meeting friends, or attending a social group or class.



hysical

Includes needs such as eating, sleeping, drinking, exercising, washing, dressing etc. May be a rapid change from being totally independent to needing help with simple tasks.



otional

These needs may be easier to recognise. Expression of sadness, anger, loneliness, anxiety, depression, confusion and others. Some may report positive feelings such as being 'happy to be alive'.



ind

May seem slowed down or less sharp if someone cannot attend school or work for a long period of time. May worry more, e.g. about money if they are unable to work, or if they need to support others. Hobbies and routines may be difficult to stick to when hospitalised for any length of time. Keeping your mind active is important for quality of life.



piritual

May question their religion or beliefs or seek comfort from them. They may not be religious, but may still have questions such as 'Why me?' or in the case of a parent 'Why not me?' They feel they are being 'punished' in some way.

Physical and psycho-social care should both be included and incorporated into the patient's care. Effective, holistic care will take into account all these needs for all patients. From admission, throughout their hospital stay, on discharge and through community follow-up, these needs should be assessed, acknowledged and met as effectively as possible.



Reflection

Looking back at our case study, reflect on and list Kev's SPEMS needs.

The learner should be encouraged to complete this section in their own time or as part of the session if time allows. They may already keep a reflective journal as part of their practice.



Task

The patient journey describes the process a patient will take from the initial trauma and injuries, throughout their time in a hospital setting to being discharged home. During this journey they will meet many professionals, both clinical and non-clinical in a variety of different settings. Using the box below, write or draw the key stages of Kev's patient journey before and after he reaches you on your ward. Or, you could think about a recent patient who has been on your ward and map their journey instead.

May involve transportation to hospital, A&E, intensive care, admission to the burns service, surgery, referral, and discharge. Try to encourage the learners to have six or more steps.



Task

Burns injuries are very sudden and may involve a long time in hospital and cause great disruption to a patient's life.

If you or someone you know received a burn injury and ended up in hospital, think about and write down how you/they might feel at each of these points below.

The time of the accident

Two horizontal dashed lines for writing.

Being admitted to the ward and meeting all the staff

Two horizontal dashed lines for writing.

Seeing the doctor to discuss your treatment for the first time

Two horizontal dashed lines for writing.

Seeing your friends and family for the first time at visiting time

Here we are looking for brief answers. This section should help the student to realise that there will be a range of emotions experienced, and these emotions may change with new events. Ideally this section should encourage students to think about how they would feel if they were in the patient's shoes.

Module 2 Recognising patient needs

Aim: to recognise and show an understanding of patients' physical, psychological and social needs.



Case study 2 – Shane

Shane has been admitted to the burns service. He is 32 years old and has a wife and two children aged 6 and 8. He had an accident at work and it is likely that he will spend at least a couple of weeks on the ward. Shane's injuries will probably leave scarring to his hands, arms and upper body. Shane usually works long hours to support his family, as they are very important to him. In his spare time he takes an active role in managing the local Sunday league football team.



Task

Using your knowledge from module 1, identify and write down Shane's SPEMS needs.

This isn't designed to be an exhaustive list but will give some indication of what the learner sees as Shane's main needs. From a tier 3 learner we would expect a justification and to be able to explain why each point is important along with the wider impact of each one. Theory can be included if the learner wishes.

Social: examples like – interacting with his children, wife, local football team, employers, colleagues, reintegrating back into society.

Physical: unable to use his hands – difficulty in eating, dressing, washing, and writing. Pain and discomfort, possible difficulties when returning home – intimate relationships, appearance of scars, being able to play/demonstrate football skills, being less active.

Emotional: examples like – sad, upset, anxious, angry, vulnerable, worried, uncertain.

Mind: being out of work for a long time, interacting with his family, participating in hobbies, his own needs with regards to his treatment options, and understanding the hospital setting. May also revolve around financial issues and worries.

Spiritual: there may be questions such as “Why me?”, “What did I do to deserve this?”, or feeling lucky to be alive. Shane may seek answers in religion or through other means; although we don't know anything about Shane's faith, it may be important to him. New dependence on family and friends may challenge his own ideals of life.

Shane and society

Shane will have feelings about himself. They may surround the trauma of the injuries, how he will cope, the way he looks, returning home and so on. However, Shane's family, friends, colleagues and other people he doesn't know will also have thoughts, feelings and beliefs about Shane. This section will explore some of these issues.



Task

Sometimes feelings can lead us to behave in particular ways. Think of another three potential feelings or behaviours Shane might have, and three feelings or behaviours society might have and add them to the box below.



Shane's feelings/behaviours	Society's feelings/behaviours
scared for himself	embarrassed – they don't know what to say
useless – he won't visit his colleagues at work	distressed
depressed	pity
anxious	they may stare and look
withdrawal – he won't go out with his friends anymore	strangers ask difficult questions
anger	shock
uncertain	intrigued
embarrassed	sympathetic
(and others)	(and others)



Task

Have a look at the situations below. These are some of the things Shane might want to do once he is discharged from hospital. What may be some of the issues that could arise in these situations? Discuss these in your group. How might Shane behave or feel? How might his friends and acquaintances behave or feel?

Leaving the hospital and going home for the first time

Leaving the safety net of the hospital – where other people may understand/have similar injuries, worries and concerns as him.
Having to return to independence, or have to rely on people to do things for him / change of roles from being the breadwinner, working 9-5 and so on.

Going to the pub to meet up with his friends for a Friday evening drink

May worry about people staring, comments, pity and unwelcome interactions with others.
Anxieties around returning to his usual activities, 'looking different', being with friends and other people who knew him before the accident. However, his friends may be really happy to see him, or could be quite overprotective.

Going back to manage the local Sunday football team

People making presumptions about his ability to cope, not being able to be the person he was before and therefore frustrated. May be a welcome relief as a return to some level of normality. Interacting with others, people who knew him 'before'.

Going to wait at the school gates for his children

People staring, whispering, pity, comments, parents acting differently to before/embarrassed. Not wanting to scare children, children asking outright questions to parents or himself, worried about other people's reactions.

Doing the washing up

May have concerns with bandages, scarring, and possibly pain. This may not yet be a task that Shane can accomplish, which may be upsetting. He may not feel like he is able to contribute to daily household tasks.

Returning to work

Unable to return to his normal position in the company due to injuries, returning after significant time off, scared as he had his accident at work, this may bring back difficult emotions. What will his colleagues think?



Communicating with patients (PowerPoint 2)

Communication

There are two main types of communication: verbal (speech) and non-verbal (body language). These two forms of communication go hand in hand. When we communicate, the majority of the messages we send to others come through our body language. This might be our posture, the way we are holding our hands and arms, eye contact and our facial expression. The other important part of communication is the 'way' we say our words, for example if we said "do you want a cup of tea?" angrily, then it wouldn't sound welcoming or caring. The words that are spoken are actually thought to be the least important when sending a message. If a carer had their arms crossed, and wouldn't look the patient in the eye, there is little chance of having a successful relaxed conversation. The most approachable carer would have a relaxed body posture, maintain good, natural, eye contact, smile and have their hands in a relaxed position by their side.

Top tip

- Think before you speak; also think about what your body is saying as well as your words.

Communication in a health care setting

For many patients and their families, the hospital environment can be a distressing and daunting place. As we have seen from module 1, patients will meet many professionals in clinical and non-clinical roles during their stay at a burns service. At times, patients may experience a lack of control, lack of dignity and understanding. We know that loss of control, unfamiliarity and high levels of unpredictability all contribute to high levels of stress. This may be accompanied by feelings of distress, pain and other complications

due to their injuries. Patients can therefore feel vulnerable during a long stay in hospital. For this reason it is very important to communicate sympathetically with the patient. This gives the opportunity to reassure them, and allow them to express their feelings and worries if they wish to.

Top tip

- Hospitals are daunting and distressing places for patients and their families. If you are meeting them for the first time always remember to introduce yourself (preferably with a smile) and say what you are there to do.

Normalising feelings

As we have seen throughout modules 1 and 2, patients, their friends and families may experience a variety of feelings and emotions throughout their time in hospital. Any patient who has experienced the trauma of burn injuries is likely to experience a whole range of unfamiliar or even overwhelming emotions. This is usually perfectly normal and understandable. It is important that the patient and staff understand and acknowledge this. A patient may also try to hide their feelings or suppress their emotions and some will try to 'be brave' or 'hold it together' for the sake of their family. As a member of the multi-disciplinary team it is very important that you help the patient to recognise that expressing their feelings is OK.

Top tip

- It can really help a patient if you tell them how they are feeling is normal.



Task

Even if you are in a role at the hospital where you don't contribute to patient care directly, or if you are busy and don't have a lot of time, you can still help to normalise a patient's feelings. Have a look at the two scenarios below with answers, and then attempt to answer the next two.

- 1 Patient** "I just feel so sad and depressed; life will never be the same again."
You "I can hear how upset you are; have you thought about talking it through with someone?"
- 2 You** "How are you feeling today?"
Patient "I don't want to bother you with how I'm feeling, you don't want to know."
You "It is alright to feel bad sometimes, you have been through a lot; have you thought about talking to someone about how you are feeling?"

What might you say if...

- 3 Patient** "I want a cup of tea now." (said angrily)
You

- 4 Patient** "Don't draw back my curtains today; I want to sit in the dark."
You

These answers should be appropriate to the learner’s job role and what they are comfortable with saying. However, we want to encourage them to think about what they would say, and how they would say it (including tone of voice), for example staying calm with the angry patient.

Working with different cultures

In your unit you are likely to meet staff and patients from many different cultures and faiths, who respond differently to illness. Some cultures express their emotions very openly and some will be much more reluctant. Some patients will have large extended families and expect lots of visitors, and some will want to be more private. The same will apply to staff members that you work with. They too may have different ways of talking about things and doing things.

Some people form opinions about others on the basis of what they look like or what they wear. Often these conclusions can be incorrect and we must be careful not to stereotype people before we know anything about them. Many of your patients may have very different ways of doing things at home compared to the hospital. They may also not like the ways and routines of the hospital as they are strange and different.

If you are uncertain about what would be best for a patient, then ask. Generally people don’t mind being asked. You may not be able to change something but it does show that you care and are interested.

Top tips

- Try not to make assumptions about the way people are used to doing things, or about how they are. The reality may be very different to what you see.
- Try to treat everybody as an individual and with respect.

Practicalities and logistics

When patients are admitted to the hospital they will be in a strange and unfamiliar environment. They will probably not have much control over their life as many things, such as waking up, meal times and visiting hours will be dominated by the hospital routine. Patients may have many questions about their new environment and it is important to know the answers to give them.



Task

What practical things are there in your hospital that patients should know about?

For example they may want to know about meal times, visiting hours, who is who, travel (for family wishing to visit), where the hospital shop is, parking regulations and so on.

If you do not know the answers to these questions please try to make time to find out, so you can help a patient and their family if they need this information.



Reflection

Think of a patient on the ward now, or who has been there in the past. How well were you able to meet their needs? Could you have done anything else?

The learner should be encouraged to complete this section in their own time or as part of the session if time allows.



Further reading and links

Clarke A (1999) **Managing the future after burns, Addressing Psycho-social Needs, a guide for health professionals.** Changing Faces.

Partridge J, and Robinson E (1995) **Psychological and Social Aspects of Burns.** *Burns*, 21(6), 453-457.

Partridge J (2006) **From burns unit to boardroom.** *British Medical Journal*, 332, 956-959.

Rumsey N, Clarke A, and Musa M (2002) **Altered body image: the psychosocial needs of patients.** *British Journal of Community Nursing*, 7(11), 563-566.

Rumsey N, Clarke A, and White P (2003) **Exploring the psychosocial concerns of outpatients with disfiguring conditions.** *Journal of Wound Care*, 12(7), 247-252.

British Burn Association: www.britishburnassociation.org

Changing Faces: www.changingfaces.org.uk

National Burn Care Group Standards for Psycho-social Care and Rehabilitation, 2008

Module 3 The wider impact of burn injuries

Aim: to continue to explore the impact of burn injuries on the patient, as well as the patient's family, friends and significant others.



Task – how patients feel

In an intense environment like a burns service when patients and their families may be struggling to get used to a new situation, people may behave out of character. The frustration of being in hospital, in pain and being away from family can be very difficult.

Imagine the following scenarios. How would you feel? How might these feelings make you behave?

We are trying to encourage staff to think about things from a patient's perspective (rather than a medical perspective). This is often a very useful learning experience.

Both your hands are bandaged. Think of the things you can't do. How would that make you feel?

You are missing your brother's big birthday party that has been planned for months because you are not fit enough to leave hospital.

You are not able to take or collect your five-year old daughter to and from school in her first term. She is very upset and does not want to go with her father/mother/friend.

These are some of the things that a patient who faces a long time (or even a short time) in hospital might not be able to do. The suddenness, the frustration and the sadness can be hard to take in and as a result people can behave differently. They can be overwhelmingly angry or sad and behave in ways that can be a surprise to them and their family. People can get really cross and edgy about small things that would normally just go over their heads e.g. whether the curtains are drawn a certain way or what they are eating. This in itself can be a frightening experience as the patient will be dealing with the unfamiliar feelings as well as a strange hospital environment.



How patients make staff feel

It is not surprising then that some patients can make staff feel irritated, angry or sad. However as a health professional you need to treat everyone the same. This can be difficult sometimes especially if the patient is directing their feelings at you.

Next time you feel angry or irritated or sad about a patient or their family, take a moment to think about the situation they are in. If you have a really strong emotional reaction to someone, it can be a sign that the patient is feeling totally overwhelmed by that feeling or situation and you are taking some of that emotional load. In an intense environment where a patient or a family is struggling to get used to a new situation this can be quite common.

Monitor your reaction to your patients and make sure you have somewhere to offload those feelings. Make sure they do not spill over into the care of that patient or other patients.

Top tips

- Put yourself in your patient's shoes occasionally. Think about how you might be feeling in their situation.
- Try not to take it personally if someone gets angry or upset with you. Remember they are probably angry with their situation, not you.
- Try not to judge. It can be unhelpful to label patients as 'difficult'. Remember it is the situation they are finding difficult.
- Look at the section on 'Looking after yourself' (page 32).



Case study 3 – Elaine

Elaine is 41. She has been on your ward for two weeks having experienced significant injuries to her face, hands and torso from a chip pan fire. Elaine is a single mother of two teenagers, aged 14 and 17. They are currently being looked after by Elaine's friends. Elaine doesn't currently have a full-time job and she supports her family by doing various part-time casual jobs.



Task

In the space below, brainstorm the key issues for Elaine. It may help to think of her and her family's SPEMS needs.

From a tier 3 learner we would expect a comprehensive understanding of the wider impact of burn injuries on the patient and the wider social context. Answers may surround:

Her changed appearance, feeling good, looking good, ability to dress

Her children; how will they cope? How well is her friend looking after them? Anxious about their needs being met

Returning to work; being unable to do the same job again, income, using her hands

Other physical injuries she has sustained; ability to hug others/physical contact

Her emotional needs; anger, resentment, loneliness, feelings of loss, bored, guilt

How will her friends and other family react?



Further information (PowerPoint 3)

There are lots of strong emotions that patients might feel and experience especially after a traumatic burn injury.

Stages of grief

Elisabeth Kübler-Ross's *Stages of Grief* (1997) is a well recognised framework for understanding loss. Although originally designed to help individuals to understand the grief process of death and dying, the same ideas can also be useful in cases where people are experiencing loss or are grieving for what they 'used' to have. The idea is that individuals can go through various stages of grief. The stages in the model aren't designed to run one after another, meaning that people can go back and forth between emotions, or skip stages. The stages are:

Denial – Individuals may avoid the issue. Sometimes it's as though they choose to ignore the extent of what has happened. They may not want to look in the mirror, participate in dressing changes or accept that their life has changed in any way. "If I ignore it, then it will go away", or "It's not as bad as it seems".

Denial can be very helpful in the early stages of recovery. It allows us to take in more slowly the psychological impact of what has happened and often our body needs the energy for the physical healing. Sometimes what has happened is so 'big' and 'awful' we need the time to get used to it. Denial becomes a problem if people are getting close to discharge and they have an unrealistic view of how they're going to manage when they get home; or if people don't want to take part in rehabilitation because they think that things are going to 'just get better'.

Top tips

- It may well be normal for patients to experience some 'denial' in the early stages of recovery.
- Work with patients slowly to help them get used to the new situation they are in.
- You may find you have to repeat things – "there may be some things that will change when you get home".

Anger - This can be expressed in a variety of ways. They may be angry with themselves or another individual, possibly for causing their injuries, or for not preventing them. "I shouldn't have been so stupid", or "I can't believe he didn't check the smoke alarm." Patients can also get angry at other people (staff, friends and families). They might be snappy, short tempered or insist that even small things are always done very precisely and get really angry if they are not.

Obviously as a staff member you do not have to accept abuse or swearing from patients or families, but try acknowledging their anger, "I know you are angry, that is OK". Or agree with them how you are going to do something before you start. Do not raise your voice or get into an argument with patients – that is likely to make the situation worse. Even if you think they are being unreasonable, think about it from their point of view. Anger is a very common phase in recovering from a traumatic injury – try to see the anger as a normal part of recovery and try not to label the person as 'just an angry patient'. Most people do not want to be angry all the time – it is just that their feelings are overwhelming.

Top tips

- If a patient shouts at you, stay calm. Don't shout back. It is likely to make things worse; try not to get defensive either.
- Negotiate if you can. It will help your patient to feel in control.

Bargaining – This may involve bargaining with themselves, their treatment options or religion. They may try and compromise with the situation, or strike a bargain. “What if?” “Could we just try that treatment?” It sometimes helps if you try and give patients as much control as you can over their situation. For example, we know that if patients are allowed to administer their own pain medication after surgery, they actually use less. Where possible allow people to try things out for themselves even if you know it’s likely not to work or is impractical. Making mistakes is often part of learning about something new.

Top tips

- Explain and agree how you are going to do things.
- Try to get your patients involved in their own care as much as possible, even if it is only small things at first.

Depression – To some extent the patient may have begun to accept the reality of their situation. They may begin to express emotions of sadness, grief, and anxiety. It can be a reflective time to understand the extent of what has happened to them and how to go on in the future. “How will I cope?”; “This is awful”; “There’s no point in going on”. We are very quick to give antidepressants to people these days but the depression that people feel after trauma is often normal. You might be more worried about the person who seems to breeze through everything. Give the person who seems to be depressed time and space. If you can, be there if they want to talk – often the most important thing is a friendly listening ear. Sometimes people can get very tearful; try not to be scared of this. Giving people permission is also important. Depression becomes a problem in rehabilitation if someone is consistently and continually so depressed and slowed that they have no energy or motivation to do anything. That is when you might want to talk to a psychological specialist staff member or suggest that a patient does so.

Top tips

- It’s not what you say; it’s about being prepared to listen.
- Acknowledge how they may be feeling, using the patient’s own language.

Learning to cope with the new situation – It will take your patient a long time to make adjustments and adapt to change. Sometimes progress can be slow and it may seem like they are not progressing. People need time to try out new ways of doing things, maybe make mistakes, and learn new coping strategies. This is where psychological help can be useful – to help someone work out new ways of coping where the old ones don’t work, or aren’t appropriate any more. For some individuals they may be able to return to work or school, or participate in family life once again. However for some it may mean a complete change of role, relying on other people, loss of independence and confidence in their own abilities. This is where regular follow up after discharge can be particularly important.

Top tips

- Help your patient to find small achievable goals. That way they will feel they are getting somewhere.
- Warn people that sometimes it may seem like “one step forward, one step back”. That is often normal.

Summary

The Stages of Grief is a useful model for understanding the patterns of emotions that patients go through when experiencing loss or change due to trauma. However, it is also important to note that not everyone will go through all these emotions in this order. In fact people may skip stages or may spend a long time in one stage. Remember that the model isn’t linear and people will go back and forth. Major life events such as a divorce can

also influence the stages. This can prove a useful tool to talk about with patients so they understand that it is 'OK and normal' to be experiencing a range of emotions associated with the trauma of their injuries.



Kübler-Ross E (1997) **On Death and Dying**. New York: Simon & Schuster



Task

Looking at the Stages of Grief model, can you identify any patients on your ward who are going through these stages?



What else may be worrying your patient?

There are many other things that can affect how patients cope and feel both while they are in hospital and after they are discharged. Here are some things you might think about.

Perceived and objective severity

Perceived severity relates to the individual's own opinion of their injury. Objective severity describes how one may 'quantify' their injuries, for example, '30% deep dermal burns'. Psychologically, there is often a difference between perceived and objective severity. It is important to remember it is how severe the patient believes his injuries to be that is key to his good or poor outcome, not the medical definition of severity. This explains why some people who have widespread injuries may be less concerned than someone who has a relatively small burn. This might seem illogical, but try not to compare one patient with another. Each patient's feelings are equally valid.



Kleve L and Robinson E (1999) **A survey of psychological need amongst adult burn-injured patients**. *Burns*, 25, 575-579.

Positive impacts

Not everyone will experience a negative reaction to their injuries, or they may not have a catastrophic impact on their daily life. Some will cope with minimal help or perhaps after reading a self-help guide. Some may report 'feeling happy to be alive' or 'it could have been much worse'. Patients may go on to be positive role models for others in support groups. Sometimes people find it very valuable to meet other people who have shared experience of burns and people can share useful coping strategies with each other.

A lot of research has been done to try and work out why some people seem to learn to cope and others don't and there is no clear answer. Sometimes it can be long after the injury (even years) that someone who seems to have coped begins to break down. This can be shocking for a patient and their family because it seems so unexpected. There is more about this in module 4.



Lansdown R, Rumsey N, Bradbury E, Carr A & Partridge J (eds) (1997) **Visibly Different: coping with disfigurement.** Butterworth Heinemann. London.

Psychological recovery and physical recovery

Psychological recovery does not run concurrently with physical recovery. Even when a patient's injuries are showing signs of improvement, or the scars are fading, he might not be feeling any better psychologically. This can be hard for patients to understand and they will often say things like, "the injuries are looking so much better; I don't understand why I don't feel better." In fact it may be that the psychological recovery can only really start after the body has stopped using all its energy on the physical recovery. When the physical recovery has taken place that may leave more time for patients to think about their injuries and the impact on their lives. Only then can patients begin to make sense of what has happened to them and how it might affect their lives and the lives of those close to them. Some people may seem to cope at this stage and others may start to struggle. Sometimes the people who seemed to cope in hospital can struggle once they are discharged.



Moss TP (2005) **The relationships between objective and subjective ratings of disfigurement severity, and psychological adjustment.** *Body Image*, 2, 151-159

Normalising

Normalising behaviours is very important to allow the patient to feel free to express their emotions. It may be difficult for you to spend time with the patient whilst carrying out your daily job role. However, a conversation about how they feel can happen any time, during a dressing change or when giving them their medication. Ensure the patient knows that how they are feeling is understandable to others, and that it is OK to cry or show sadness. Try to avoid saying things like, "don't worry" or "you'll feel better soon" because just at that moment that might seem impossible for a distressed and anxious patient; it may be better to say, "many people feel that way after going through what you have, it is perfectly normal and understandable".

Behaviours that can be difficult to respond to

Whilst it is important to normalise the behaviour of patients when they are dealing with sadness, loss and grief, it is also important to recognise when some behaviours are not helpful or acceptable.

We suggest behaviour that is abusive to themselves or others (including family, friends, staff and other patients) is recorded and dealt with in a way appropriate to your service or trust policy. Patients need to be made aware if their behaviour is inappropriate. Also, if a patient displays any suicidal thoughts or actions, this should be reported immediately. Patients may say things like, "I can't believe this has happened to me, I wish I was dead". While this comment may be upsetting for people to hear, it reflects the depth of a person's feelings and how overwhelmed they feel. There may not be any real threat of carrying out a suicidal wish. However, it can be difficult to be sure, and you must ensure you are up-to-date on any trust/hospital policies in dealing with suicidal (and abusive) patients, and get a suicide risk assessment completed as soon as possible.

If you are worried about a person's behaviour or some of the things they are saying, be sure you know how to seek help from the psychological specialists that work in your service.

Top tip

- Do you know what your policy is for helping people who might be expressing suicidal ideas; or people who are abusive?

Traumatic stress

Your patients may well be experiencing symptoms or signs of traumatic stress as well as the physical and emotional problems arising from their burns. The most common symptoms are nightmares or flashbacks - feeling that they are 'reliving' parts of the accident all over again. These experiences can be very vivid and frightening, and it can take patients some moments to 'come back to reality'. Patients may also be very hypersensitive to sudden noises, unexpected activity, and sounds and feelings around them. It is as though their mind and body is noticing every single little thing and this can be very exhausting. This can also be associated with high levels of anxiety.

People might feel very 'numb' and many may describe the accident as 'all being in slow motion'. Some people may have no memories of the accident at all and this is called anterograde amnesia. This is also unnerving as people will often want to piece together what happened to help make sense of it.

With time these problems should diminish in intensity and frequency.

What is Post-Traumatic Stress Disorder (PTSD)?

At its worst traumatic stress can develop into Post-Traumatic Stress Disorder which is a serious psychiatric condition. There will be other symptoms such as an inability to stop thinking about the accident or being constantly reminded of it, lack of interest in doing anything, lack of motivation, and feeling very flat (no highs or lows of emotion at all and feeling distanced from everything that is going on). People with PTSD will often describe it like 'being in a bubble' or 'behind a cloud'. PTSD cannot be diagnosed until at least six weeks after the trauma and may only become evident several months later when problems should have resolved. This patient should be referred for specialist help.

Of course it might be hard to distinguish which symptoms are due to the effect of the injuries and which are part of a trauma response. In a way this doesn't matter. The important thing is that you and your patient understand that this kind of reaction might be normal for a while. If the problems are continuing and your patient is very distressed then seek help from one of the psycho-social specialists in your service.

Top tips

- Reassure the patient who is suffering from a nightmare or other form of re-experiencing. Calmly keep reminding them where they are, that they are safe and stay with them till they are aware again. Sometimes it can help to encourage the patient to concentrate hard on something in the room like a personal item or to touch something like the bed or bandage.
- Try to avoid sudden actions or noises when you are around your patient. Tell them or warn them about what you are doing especially if you have to make a sudden noise. Try to work slowly and predictably if you can.

Families

So far we've just talked about the patient and what they might be feeling. We must remember that families will be feeling many of these things too. They are likely to go through the stages of grief that we have talked about and have many of the same questions. After all they may feel they have 'lost' the person as they knew them, especially if they are likely to have a long term disability or scarring as a result of the accident, or require many treatments over several years. Families will have their own ways of grieving and will not experience the same emotions at the same time as the patient. They may have feelings of guilt and

be preoccupied with thoughts about how things could have been different. Remember too that families may have been involved in the accident and may also be experiencing symptoms of traumatic stress.

All this can sometimes make for misunderstandings and tensions between family members. You can do a lot to help patients and families understand this and encourage them to keep communicating.

Top tips

- Remember that families are also likely to be experiencing strong feelings about the accident and what has happened. They may be experiencing their own 'stages of grief'.
- Try to encourage families to keep communicating with each other.
- Families may need help as much as your patient – in some situations it might be just as appropriate to talk to a family member or suggest they talk to one of the psychological specialists in your service.



Task

Going back to our earlier case study, below are a series of scenarios. Discuss and think about what you might do in each situation. What might be going on for Elaine and her family? We have given you a couple of questions to think about for each of the situations below.

1 You've noticed Elaine is displaying aggressive behaviour when having her dressings changed. She is being rude and dismissive to staff. She also avoids looking at her injuries. You may want to spend a couple of minutes discussing what you might say to Elaine. Why might she avoid looking at her injuries? What can you do to help?

Answers may surround:

Denial, wishing they would 'just go away', stages of grief

Feels uncomfortable looking at her injuries

May be able to help by asking her why she doesn't look, if she would like some more information about her injuries/dressings etc

Telling her it is OK to not want to look, to feel sad or angry with her situation, that you are happy to listen/acknowledge difficulties

Be patient and understanding about outbursts (however, challenge abusive behaviours).

2 Elaine's 17 year old daughter came to visit the hospital a while ago and hasn't been back since. What might you say to Elaine? Is it important to encourage her daughter to come back? If so, how might you do this?

Answers may surround:

May want someone to call the daughter to check she is OK, she may be finding it hard to cope herself (for a number of reasons – new role in the family, aversion to mother's injuries, angry, upset, dismissive...)

Elaine may want to call her herself – may need help in facilitating this

Her daughter is an important source of social support for Elaine

Find out if there are social workers involved with the family – maybe they could help

Speak to Elaine's friend about how her daughter is coping.

3 The team have started to consider a discharge plan for Elaine. Identify some potential problems that may arise when Elaine is discharged. What things might help Elaine to get used to life back home again? What are some of the things she might worry about?

Answers may surround:

- Return to home where accident happened
- Return to employment
- Taking care of two teenage daughters
- Practical needs: washing/dressing...
- Continued support in home setting, possibly family therapy, advice on work/benefits.

Important points to remember

- It is important that patients are allowed to express their feelings.
- As patients' injuries get better, the way they feel may not.
- Families may express more negative views than the patients themselves.
- Some people may require a bit of time and space to get used to their new appearance; this is OK.
- Even if people get really tearful then it doesn't automatically mean they are suffering from depression.

Notes

A large rectangular area with a dashed border, containing numerous horizontal dashed lines for writing notes.

Module 4 Coping with change

Aim: to investigate factors that predict good psycho-social outcome and the role of the health care professional in facilitating this.

Predicting patient outcome

Some patients will seem to cope psychologically with what they have experienced and their injuries. However, others may seem to struggle to cope. Some of your patients may just need positive comments from a close social support network, or a patient support leaflet on discharge. Other patients may need to talk through their feelings in a greater depth with staff or members of the specialist psycho-social team.

How can we predict which individuals will need what level of help? Unfortunately this is not an exact science and we are all very individual in the way we respond to trauma. However researchers have looked at some factors that may play a part in how patients cope. This can help us as health professionals to identify individuals who may be at risk of significant psychological distress.



Task

Think about patients you have cared for on your ward. Consider those patients who have coped well with a change in their appearance and those who have struggled. Use the space below to discuss why you think those that coped well did so, and some of the reasons for those who found it harder.

Answers may vary according to which patients they choose to discuss, but are likely to include:

Strong, close family and friends to provide support

Consideration of someone's spiritual/religious beliefs/faith

Patients' attitude to appearance/beauty – how important it is for them

Availability and uptake of psychological support

Patients' communication skills

Optimistic personality

Financial situation.

Handwritten notes in a dashed box:

- Answers may vary according to which patients they choose to discuss, but are likely to include:
- Strong, close family and friends to provide support
- Consideration of someone's spiritual/religious beliefs/faith
- Patients' attitude to appearance/beauty – how important it is for them
- Availability and uptake of psychological support
- Patients' communication skills
- Optimistic personality
- Financial situation.



Task – factors influencing positive coping

Below you will find a brief description of several people with different backgrounds. These experiences may or may not affect how they cope psychologically with their injuries. Read through the scenarios and complete the task below.

On the opposite page you will find a grid. Place the people listed below and opposite according to whether you think they may cope well or whether they may struggle to cope. You only have one fact about each person, so it is not representative, and there is no right answer, but it should get you thinking!



Darren has a great easy manner with people that means he makes friends easily and is a good listener



Rakesh is 17 years old



Brian has always been happy to learn to change his own dressings and tries to remain hopeful about his future



Moses doesn't seem to have anyone who cares for him



Dr Davis has published many successful books on 20th century politics

Jane has always worried what people think of her



Victoria wouldn't dream of going down to the shops without her make-up on and spends a lot of money on beauty treatments



Percy is well respected by his peer group



Sarah left school at 14 and never did very well



Derek can cover up his scars with clothes



Tracey's friends have always liked the way she looks, but she disagrees



Thomas has a close family who have understood and heard his concerns in hospital

Positive coping

The top row should contain the person you think is most likely to cope

The second row should contain three individuals that may cope well

The third row is for those you are unsure about

The fourth row should be three individuals who may struggle to cope

This row for the person you think will struggle the most

Negative coping

Niraj's family says his scars can hardly be seen



This task is designed to encourage discussion and it is important to note that there is no right answer. It should encourage the learners to discuss the factors that may influence positive coping and point out some of the other factors that are unhelpful. Learners should be able to consider the different factors but must also understand that these factors will never be in isolation. The learners may be able to justify their answers by using previous patient examples.

Factors predicting positive coping (PowerPoint 4.1)



How did you get on?

Although the task just completed may be quite simple, it does demonstrate that some factors may help to influence positive coping in individuals. Many individuals will have a variety of factors (rather than just one as used in this task) that may help to predict whether they may cope well or may struggle. These factors are discussed in more detail below:

Social support (Moses, Thomas): This is a very important factor. Numerous studies show that having a strong social support network can help the individual meet their psycho-social needs. Having a good social support network also helps the patient steer clear of the issues surrounding social avoidance and associated problems of withdrawal. In our examples, Moses might be at risk if there seems to be no one who is around for him. Thomas is clearly able to communicate well with his family and this may well help him when he is discharged to get through some difficult times.

Communication/social skills (Darren): Several studies have suggested that social skill is central to managing the impact of a disfiguring injury or disease, and most importantly, that these skills can be learned (Robinson et al 1996). If the patient has good social skills, then this will facilitate the ability of others to look beyond appearance, and maximise social support. These kinds of skills are likely to stand Darren in good stead to manage the impact of his injuries.

Visibility/disguiseability (Derek): Although you might think it would be, visibility is not a strong predictor of adjustment. The visibility of scars can exacerbate distress but some people will be equally distressed by scars that they can cover or hide. The ability to cover up scars can be a very powerful coping mechanism, but might be superficial and hide a greater vulnerability underneath. Those coping less well may wear heavy clothing even during the summer, or excessive make-up for example. Overall, disguiseability may have an impact, but is not a strong predictor of positive coping.

Perceived severity (Niraj): Perhaps the most common myth about outcome following burns is the perception that the seriousness or extent will be proportional to psychological distress. Kleve and Robinson (1999) highlight the importance of 'perceived severity' or 'noticeability' rather than objective severity as a critical indicator of good or poor outcome. In other words, it is how the individual interprets the injury that is critical to their long-term recovery. We cannot assume that because Niraj's scars may be a lower percentage or barely visible that he will automatically cope better.

Education (Sarah, Dr Davis): Your level of education does not serve to predict good or poor adjustment.

Age (Rakesh): There is some evidence to suggest that appearance concerns do decline with age, however this is open to much interpretation. Throughout our lifespan we go through many major life events. A number of these occur during teenage and young adult years. It can be especially difficult to cope during times of transition and change in our lives (e.g. marriage, bereavement or moving home). It can also be difficult to cope when there are strong influences to be 'like our peers'. This is especially so in teenage years. However, studies suggest that large numbers of older people have appearance related concerns too.

Optimism (Brian): Research has suggested that the more optimistic a person is, the more likely they are to adjust.

Social acceptance (Percy): This relates to how one is accepted in their social group. There may be specific social ideals and the closer someone is to these social ideals the more likely they are to cope. Percy's acceptance by his peer group may help him to cope with his trauma and injuries.

Fear of negative evaluation (Jane): Some individuals may place a larger weight on the opinions of others over their own, and this may be more noticeable in certain social situations. This may in turn increase their

anxiety. Jane may worry more than others about how other people will ‘accept her’ with her injuries and this may make her vulnerable.

Involvement in treatment (Brian): The more involved you are in your treatment and given informed choices about your treatment plan, the more likely you are to cope better in the long term.

Perceived importance of appearance (Victoria): Some people place much greater value on their external appearance and might have a very strict idea about what it takes to look ‘normal’. We know for example that people with anorexia overestimate their weight and figure because they have a very ‘narrow’ idea of what a ‘normal’ weight is like. If you perceive your appearance to be fundamentally important to you and your place in society you may be less likely to cope with a change to that appearance, especially if you perceive that to be negative. People who have always been uneasy about their body image may be more vulnerable to problems in coping. Victoria might be at risk if she has always been unhappy with her appearance and looking for ‘perfection’.

Appearance discrepancy (Tracey): If the way you view your appearance is significantly different from the way others view you, then you are less likely to cope. Other people saying “you look great” is not enough. Our body image and our confidence about it comes from a deeper psychological ‘satisfaction’ which other people’s encouraging comments cannot change that easily.

Strategies for support (PowerPoint 4.2)



Sometimes you will hear people talking about ‘adjustment’. You may even say it to yourself that certain patients may be adjusting well or adjusting less well. However we have tried to avoid the concept of ‘adjustment’. It can suggest that people will eventually feel completely OK about their injuries, that they can get back to their old selves and put the psychological distress behind them. This may happen for a few people. However, what is far more likely is that, even in the best of circumstances, people learn to cope with the new situation as best they can. Even years after the trauma, a situation can come up which will take someone back or catch them by surprise and they will have to learn new coping strategies to deal with that new situation. It is therefore best to think of the coping process as lifelong and that people may get used to their new circumstances.

The psycho-social care and understanding that you can offer while someone is in your service is the beginning of that and will really help people to develop coping strategies that they will be able to take out of the hospital and into their lives.

It is often very simple things that will help and, as we have seen in the previous modules, acknowledging someone’s distress and sense of helplessness is often the most important thing.

This section will cover some strategies for supporting patients. It will then go on to look at the psychological support available in your service and what support they provide.

3-2-1 Go!

This model is suggested by *Changing Faces*, the UK disfigurement charity, as a useful tool to help prepare people for discharge and to ‘get back’ to their lives and society. Many burns patients will have spent a long time in hospital which can provide a ‘safe’ space away from the trickier issues of coping with other people’s concern, reactions or questions.

Many burns survivors will get asked questions about their burn injuries and scars, how they got them, what happened and what the treatment is like. If patients are not prepared to answer these kinds of

questions, it can leave them feeling off guard and vulnerable. As part of the social skills training programme, *Changing Faces* suggests using 3-2-1 Go! as a tool. This gives patients a few stock answers to prepare them for questions. It stands for:

- 3 things to do if someone stares at you;
- 2 things to say if someone asks you what happened;
- 1 thing to think if someone appears to turn away.

If patients are prepared to say or do something that feels 'right' for them then this can be a useful strategy for increasing confidence and decreasing vulnerability on discharge.



Task – 3-2-1 Go!

Think of a patient on your ward that you know well and try to come up with some suggestions that might help them. Alternatively, complete this for Elaine (case study in module 3).

Use the space below to fill in your suggestions.

■ 3 things to do if someone stares at you

Answers may include... smiling back, gaining eye contact to let them know you are there, looking away, head nod...

■ 2 things to say if someone asks you what happened

Answers may include... opening up the conversation, "I'd rather not talk about it thanks", "I got burned and now I have to be careful in the sun", "It's just a burn"

■ 1 thing to think if someone appears to turn away

Answers may include... self soothing, thinking of a holiday, nice places, friends/family



What else can you say?

It can also be helpful to remember certain little tips when you are providing support to your patients.

The most important thing is to listen to people's worries so that they can be understood and contextualised, rather than offering sympathy or agreeing with the person. You might feel like you want to cheer people up or help them feel better at that moment, but this isn't always helpful in the long term. It is OK for you and the patient to stay with the sadness and to suggest it might be helpful to talk to someone about it.

Remember

- We don't 'get used' to a changed appearance. Sometimes it's as if you see the scars afresh again every time you look in the mirror.
- No amount of other people telling us we look OK makes much difference to how we really feel inside. In fact this can trigger really strong negative emotions when what others say is so different to what the patient feels.



Task – saying the right thing

Even though we mean well there are some things that we will commonly say that do not necessarily help people to cope.

Look at the following comments. You may hear health professionals or friends and family saying the following things. What is the problem with saying something like this? Can you think of something else that you might say instead?

“I’m sure you’ll get used to it”

“You sound like you are struggling with your appearance right now; do you want to talk to someone about it?”

“I’m sure people won’t notice”

“People may stare but they are often just curious, and may wonder what happened. They’re not being nasty.”

“Your scars will fade”

“It must seem bad now but we do know that your scars will change over time and you may feel differently then.”

“It’s amazing what plastic surgery can do these days!”

“Sometimes people say things about surgery not because they think you are going to need it but because it hurts to see you in pain or struggling to cope and they want to make you feel better.”

Top tips

You may find some of these comments helpful:

- “It sounds like you are worried about how you are going to look in future. This is very understandable at this point in time.”
- “It sounds like you are concerned about what other people may think or feel about your injuries. Did you want to talk to somebody about it?”
- “Your skin is going to need time and care to heal as well as it can. Right now you could focus on things that you can influence like trying not to pick, eat well, drink well, doing your physiotherapy exercises. The rest is up to your body.”
- “We have someone who can help you prepare for going back home when you are ready, especially if you are worried about others seeing you.”

Providing helpful information



Providing timely, realistic and informative advice for patients is also important. Patients often struggle psychologically with the following:

Lack of predictability: the burns trauma your patients have experienced is almost certainly unpredictable, unintentional and completely sudden. They may have complex needs as a result of the trauma associated with their injuries and these needs may vary and change on a day-to-day basis. Their daily routine is also likely to be changeable for a while. This unpredictability might extend after leaving hospital when people will find it hard to predict people's reactions to their burns or scarring.

Lack of familiarity: a patient is unlikely to be familiar with the hospital environment and the routine of a burns service. This may also extend to the various job roles of staff members, and changing shift patterns.

High rate of change: this can certainly be the case early in treatment when there can be fast changes to a person's medical condition requiring different treatments and care plans. Post discharge there may also be many other changes to routine for a patient and their family to contend with.

The three factors above all increase a patient's psychological vulnerability.

You can do a lot to help ease this. You can ensure patients receive information about their care and treatment. This can help to decrease their psychological vulnerability. The information can be given to them through a variety of methods and on several occasions, on admission, ward rounds, via patient information leaflets, and via volunteers or named nurses.

You may want to ensure some of the following points of information are given to your patients at various stages throughout their patient journey, and if not in person then in a patient leaflet for them to refer to.

- Treatment options
- Ward and service staff – who does what and why. Photographs?
- Introduction to inpatient psychological services
- Ward housekeeping, for example: meal times, changeover times etc
- Support groups
- Patient stories (positive role models)
- Expected feelings (to normalise)
- Access to spiritual services and staff.



Task – information needs

Can you think of any other information your service gives to patients? Do you have any ideas about any new initiatives your service could try to help patients in this way?

This should be related to the service and the staff/time available.



Looking in the mirror

There may be guidelines on your unit for supporting patients. If so, use them and work with your team closely.

This can be a difficult moment for patients and their families. The appearance of burn injuries during treatment and healing can look really bad to patients and families, and it can be hard to visualise how things will improve as healing and recovery takes place. There are some things you can do to help your patients especially when they are looking in the mirror for the first time.

- Make sure you feel comfortable doing this. Don't worry if you would rather a more specialist member of staff worked with the patient, and say so.
- Work with your multi-disciplinary team and your patient to think about when to start.
- Prepare your patient for what they might see; it is important to take time over this.
- Ask them if they would like you to describe what you see first.
- Make sure you have the time set aside and take as long as is needed to support your patient.
- Make sure you have a private space and you will not be disturbed.
- Your patient may want family members there.
- If you feel uneasy about answering any questions then suggest someone else who can, or a specialist member of the psycho-social team.
- Have a look at the section 'Saying the right thing'. This might give you some ideas on what to say.

Looking after yourself



Working for a burns service can be hard. It can be difficult seeing people every day who have been severely injured, in pain or distressed. It can be emotionally demanding work.

It is therefore very important that you look after yourself. Your ability to care for your patients may suffer and you may experience symptoms of stress and trauma yourself.

This in turn may start to affect your own life, relationships and health.

Keep an eye on your own feelings. Notice if your normal behaviour or your response to your patients or your colleagues seem to change (see the section 'How patients make staff feel') especially if you seem to be irritated by small things that wouldn't normally worry you. Similarly notice if you seem to 'take work home', can't stop thinking about work issues or patients, or your behaviour or your relationships seem to change for no obvious reason.

Sometimes you and your colleagues may feel a need to let off steam about your patients or your job. This is OK and there should be a space in your service to do this that is confidential and away from patient areas. It can help if you reflect on your reaction to your patients and share your thoughts with your colleagues. Try not to bottle things up but have a chat about things.

There may be times when you are more than usually affected by patients, their circumstances or the severity of their injuries. It is tough seeing people in distress every day. If you feel this is affecting you, it is not a sign of weakness or that you are not doing your job properly but it is a sign that you probably need to have a chat with someone and take some space for yourself. Sometimes when there are especially distressing situations the psychological specialists may offer a time to 'debrief'. Take up this opportunity if it is available to you. You will discover that many other staff probably feel the same and it can be very supportive to know that you are not alone.

'Burnout' is when staff in caring professions are persistently emotionally exhausted and have a reduced sense of accomplishment by doing their work. This will then begin to affect patient care. If you believe this to be happening to you, or to one of your colleagues, seek support from your manager.

Supervision: There should be an opportunity to talk through some of these issues with your colleagues in a safe and confidential way. This should be separate from your manager and your appraisal. It is important you allow time to express some of these feelings as a team otherwise it can affect patient care and everyone's performance, individually and as a staff team.

Top tips

- Switch off from work when you are off duty. Try to do something you really enjoy that will help you unwind.
- Take the leave that is available to you.
- Notice how you feel with the patients. Have a chat with a colleague or a supervisor if you feel you are getting short tempered or irritated.
- Notice and acknowledge a change in your behaviour e.g. increased anxiety, tension, alcohol use, irritability or a different pattern to sleeping or eating.
- It is OK to feel sad; sometimes staff can also get tearful. It is not a sign of weakness. We are all human and cannot always switch off our feelings.
- Use supervision if it is available to you. It will help your ability to care empathically for your patients as well as improve your own sense of well-being.

This section should be expanded to include the specific support services for staff available in your service, or this may be a good place to encourage reflection.

Referral to psychological services



Task – what are the referral systems in your service?

This should be clear for the tier 3 learners, however this is a good place to check their knowledge is up-to-date.



Reflection

Think of a current patient and what strategies you (or someone else) might use to support them.

The learner should be encouraged to complete this section in their own time or as part of the session if time allows.

Think of something that you have covered in modules 3 and 4 that you can use in your work with your patients.

The learner should be encouraged to complete this section in their own time or as part of the session if time allows. The tier 3 learners may choose to skip this until after completing module 5.



Further reading

Bessell A, & Moss TP (2007) **Evaluating the effectiveness of psychosocial interventions for individuals with visible differences: a systematic review of the empirical literature.** *Body Image*, 4, 227-38.

Birdsall C & Weinberg K (2001) **Adult patients looking at their burn injuries for the first time.** *Journal of Burn Care & Rehabilitation*, 22(5), 360-364.

Clarke A, & Cooper C (2001) **Psychological Rehabilitation after disfiguring injury or disease: investigating the training needs of specialist nurses.** *Journal of Advanced Nursing*, 34, 18-26.

Fleet J (1992) **The Psychological Effects of Burn Injuries: A Literature Review.** *British Journal of Occupational Therapy*, 55, 198-201.

Gilboa D, Bisk L, Montag I & Tsur H (1999) **Personality traits and psychosocial adjustment of patients with burns.** *Journal of Burn Care & Rehabilitation*, 20(4), 340-346.

Kübler-Ross E (1997) *On Death and Dying*. New York: Simon & Schuster

Kleve L, & Robinson E (1999) **A survey of psychological need amongst adult burn-injured patients.** *Burns*, 25, 575-579.

Lansdown R, Rumsey N, Bradbury E, Carr A, & Partridge J (eds) (1997) **Visibly Different: coping with disfigurement.** Butterworth Heinemann. London.

Moss TP (2005) **The relationships between objective and subjective ratings of disfigurement severity, and psychological adjustment.** *Body Image*, 2, 151-159.

Reeve J, James F, McNeill R (2009) **Providing psychosocial and physical rehabilitation advice for patients with burns.** *Journal of Advanced Nursing*, 65(5), 1039-1043.



Module 5 **Psychological aspects of burn care**

Aim: to explore other factors that predict or hinder psycho-social outcome and to discuss the role of psychological therapies in providing patient and family support.

Whilst some patients may benefit from a close social support network, and some from reading through a patient support leaflet full of useful information, others will need more structured psychological and social support in order to address their concerns. This section cannot deal with every eventuality, but it raises some of the wider concerns involved in the management of complex cases. This will take the basis of five case studies for discussion in groups. We suggest you pick three out of the five case studies that are most relevant to your service and your learning needs, and spend 15 minutes on each.

We have also provided a comprehensive reading list of burns literature for you to access to inform your future practice.



Task

Patients will present with many complex needs including pre-morbid factors. Use this space to consider some of the more difficult issues you have come across in your practice, or those issues you think you may come across in the future.

Learners may come up with many different factors here; these might include:

Issues of capacity. The ability for people to make decisions for themselves, especially if we feel they would go against, or refuse medical advice or could present a risk to themselves or others. Pre-morbid mental health problems can affect people's ability to make decisions and our treatment of them.

The expression of suicidal ideas and the difficulty in distinguishing between what people are saying through distress, and when they genuinely have an active suicidal ideation. A discussion should also revolve around how to respond to both behaviours.

Negotiating difficult behaviours such as abuse to staff or other patients. Ensuring that staff practice is consistent and that all staff are aware of policies to respond to these behaviours.

Negotiating with patients about smoking (and other unwanted behaviours) and whether there is any way in which they can be given permission to do this if essential.

Communication, for example, breaking bad news and ensuring staff are consistent with the information they are imparting to patients and families. Ensuring staff practice is also consistent throughout the provision of psycho-social care.



Case study 1 – John

John is 24, has mild learning difficulties and displays autistic behaviour. He struggles with verbal expression of his thoughts and feelings. However he is able to participate in a one-to-one conversation appropriately. John has always had a fascination with fire; this has become more extreme as he has got older and he is becoming more of a danger to himself and others. John has been admitted to the burns service three times in the last year with burns to his hands and face. His injuries are self-inflicted, a way for John to express his anger and frustration. John has previously refused to see a psychological therapist. However his parents are now insisting on it. His parents are his primary carers.



Task

- 1 Summarise your key concerns about John and his parents

This is a complex case and likely to involve a number of agencies. There are two key issues: the short term and longer term management of John and his family, as well as addressing the preventive issues of safety. In the longer term is there a need for involvement of social services for planning future care for John should it be necessary?

Concerns for John:

1 His ability to express himself. It is important for the staff to find the best way of communicating with John while he is on the ward, not only because it may be an opportunity to work with him about the longer term problem, but also so that he can communicate about his current treatment. There may be staff who have the ‘knack’ of working with him. Has speech and language therapy, occupational therapy or play therapy been involved in the past as a means of trying to find creative or alternative means of communication?

2 Does he understand the consequences of his ‘behaviour with fire’ and that it leads to his burns and his admission to hospital? Is this something that needs to be worked on with John on an individual basis?

3 Does John need some help to find safer ways of expressing his anxiety and frustration? Can a therapist work with John on a longer term basis to help him? Can this work be extended to his parents together with John? Perhaps they are not aware of community services and opportunities that are available.

Concerns for John’s parents:

1 That they are anxious and upset by their son’s behaviour. They may also be embarrassed at what people might think, for example, it is their inability to cope that is causing these repeated episodes.

2 How are they managing John at home – do they need input from a therapist to help with this?

3 This is likely to need a consistent response from the service and one staff member working with them in particular. A psycho-social specialist might be able to work closely with them to develop their coping strategies and address their worries about John's future management.

Perhaps the optimum approach is for a specialist to get a really clear picture of what is going on for John and his family – this may inform future management but may also be therapeutic in itself.

2 Discuss your role in John's care

Of course this will depend on the learner's role within the service. Some of the key points to consider for all staff working with John are:

1 A consistent approach to communication using any suggestions communication specialists make.

2 A consistent approach to responding to John's behaviour (appropriate and inappropriate). Although it may take time and effort to train and make staff aware, it can pay dividends in terms of minimising 'disruptive' behaviour that is time consuming and anxiety provoking.

3 Think of the things that people with autism might need – maintaining routine as much as possible, within the service and getting anything he needs from home while he is an in-patient. Involve the parents to help you achieve this as they know him best. Even if they do not always seem to be coping, don't dismiss this as they have a value to you and your staff.

4 Ensure good communication with John's parents and other key people in his social network. Written details of key communication issues might be helpful for all staff working with John; these can be placed in his notes.

5 Try to minimise interruptions and avoid situations with lots of people. John may find this difficult.

6 As a psycho-social therapist, a key role might be to manage this consistent communication and supervise other workers who are working with John, also involving liaison with outside agencies. It might be helpful to minimise the staff working with him so that there is more consistency and less uncertainty for John.

7 Perhaps John's refusal to engage with therapists in the past is because he hasn't found someone he can work with effectively. People with autism can take time to form trusting and effective relationships. It will take patience to find the appropriate staff member to do this and perhaps the staff need to think laterally about finding someone to work with John – not necessarily a specialist but someone who can receive supervision from a specialist. Is there someone outside the service who already has a good relationship with John – a care worker? Friend? Volunteer?

3 John has a case conference coming up. The convenor has asked for your thoughts and feelings on how this case should be managed including the role of psychological therapies. What would you suggest?

This will depend on the service's provision of psycho-social care and the therapeutic inclinations of staff. Possible ideas:

1 A clear analysis of the problem and the recommendations for future management.

2 Working with John and his family on approaches to minimise his interest in fire and to understand the dangers. A behavioural approach might work, or play therapy or a creative approach?

3 One-to-one work with John and a specialist with experience and an interest in working with people with learning difficulties.

4 The use of outside agencies that have the facilities and expertise to help John and his family. There may be questions and issues about the possible involvement of John and his family in the case conference.

These points, and others, may have come up in your answers:

1 How is John able to express himself? Is he able to understand his behaviour and the implications? Who does John relate to well? How are his parents coping? Do his parents need more help and support at home? If so, what form might this take?

2 What approach to communicating with John are you going to take? What about his behaviour (appropriate or not)? What about his routine? What about significant others – parents etc?

3 Analysis of John's case, overview of therapeutic approaches that may help John, involvement of outside agencies and the multi-disciplinary team and recommendations for future management.



Case study 2 – Vivienne

Vivienne is 67 years old and has struggled with her alcohol dependence since her husband left her 20 years ago. Vivienne had counselling for this at the time but she didn't find it very helpful. She has been admitted to your service having fallen asleep whilst smoking a cigarette in bed. She has extensive burns to her body, however it is not anticipated that she will have any significant functional impairment. Vivienne has no children and no obvious close social support network. Her only visitor whilst in hospital has been her niece who has been to visit a few times. She is trying to do her best but lives a long way away and has dependent children. Vivienne appears to be fearful of being discharged back home and turns away whenever the subject is raised.



Task

1 What are the priorities for Vivienne's psychological support?

Vivienne is vulnerable on a number of counts: social isolation, alcohol dependence, possible depression. What are the risks associated with her being discharged? Her fear of being discharged is likely to be realistic and indicative of some level of insight into her situation even if she cannot quite express this. As discharge gets closer she may start showing behaviours that could be related to avoidance, such as poor motivation for rehabilitation, withdrawal or even expressing suicidal type ideas. It may be that she is still grieving for her husband and the counselling that she had at the time was not helpful for her.

It may be helpful to look at short term goals of how you support her on the ward and what continued long term support might be available to her post discharge.

To prioritise the areas that Vivienne needs help with will largely depend on the analysis of the problem and what the root cause for her difficulties might be. As an out-patient these might be aimed at addressing the social isolation and perhaps offering her some 'bereavement' work. She may need to be engaged with alcohol services, but is this appropriate for a lady whose dependence on alcohol may stem from loneliness and other issues? Is it appropriate to help her stop smoking? It is unlikely she is able to engage with either of these behaviours while on the ward.

2 How might you begin to address Vivienne's psychological needs whilst she is on the ward?

This might be a slow process of engaging with Vivienne and working with her on a one-to-one basis to help her look at her fears and find new ways of managing whilst she is back home.

While she is on the ward perhaps it can be used as an opportunity to reflect on events and issues that have led her to be where she is and what she sees as the key influencers on her current situation.

She is likely to need support as an outpatient and this may need planning and reassurance that it will be available, and where it will come from.

There may be debate about the appropriateness of offering Vivienne support to help her with her alcohol dependence and her smoking given that these behaviours might stem from her situation back home, and she may continue to be vulnerable whilst back home.

No details are given in the case study about how habitable Vivienne's house is following the accident. This might be contributing to her fears, and is this problem being addressed by anyone?

3 How might you help prepare Vivienne for discharge and independent living?

A lot of this will depend on the help that she is offered whilst an in-patient but perhaps an important consideration here is that good preparation and Vivienne's involvement and 'buy in' along the way will help to ensure safe, sustainable and positive discharge. Ensure a collaborative approach, allaying her fears that decisions will not be made without discussion with her.

Perhaps the opportunity to spend short periods at home before final discharge might help too. She may need to see the state of her house and a graded approach to reintroducing her to independent living.

Introducing her to or suggesting community groups that can offer her social support. Does she need carers or volunteers to visit every so often to support her?

What ways can her niece help? This may not be practical with her other commitments but she may have some ideas about what Vivienne may want.

Does she need referral to other agencies (e.g. social services or older people's services) to maintain support after discharge? Would bereavement support help her?

A slow, planned approach that doesn't try to address too many problems at once will help. It is also important to be clear about goals and priorities, otherwise Vivienne may feel overwhelmed.

These points, and others, may have come up in your answers:

- 1 What are Vivienne's vulnerabilities? What is the timescale for her treatment and how can therapy support this, especially around discharge times? What are the short term and long term goals? What other agencies could be involved (alcohol services etc)?
- 2 Starting to find ways to cope after discharge when an outpatient. How about returning to her house after the fire?
- 3 What plan will work for the team and the patient? Can her niece get involved? What other agencies can be involved? Slow and planned approach to her rehabilitation.



Case study 3 – Farah

Farah is 37. She sustained significant burn injuries to her chest about six months ago when her hot water bottle burst. Farah has come back to see you because since the accident she has been finding it increasingly difficult to enjoy an intimate relationship with her husband. Prior to her accident their relationship was happy, relaxed and supportive. She now won't undress in front of her husband, and insists on the light being off when they are together in bed. Farah is upset that this has become a problem for her.

Farah's friend Joyce has previously had CBT for her flying phobia. This was a useful method for Joyce and she has suggested that Farah may benefit from similar help. Farah would like to know more about whether CBT could help her.



Task

- 1 How would you answer Farah's question?

Farah's request for more information is a clue that she has some worries and concerns. Listen to Farah's question even if you think it is inappropriate and you do not think CBT would be helpful for her. You might ask how she would like CBT to help her and what sort of help her friend Joyce received (you do not necessarily know what Farah's understanding of CBT is). Try to get a better understanding of Farah's current worries about the intimacy with her husband. What has changed since the accident? How have her feelings, behaviours and actions changed since the accident? Have her husband's feelings, actions and behaviours changed since the accident? Has she talked to her husband about this at all? Does he know she is seeking help? If so, what has he said? What are her fears and concerns about undressing in front of him? You might try to get an idea about the reasons for this e.g. whether intimacy is painful, or she is fearful of rejection, or he may be scared of hurting her. Suggest that even if CBT may not be helpful for her, there may be other ways in which she can be helped with this kind of problem.

- 2 What are the advantages and disadvantages of using this approach with Farah?

Advantages: If this problem is about Farah's fears of rejection and she has some clear thoughts about her body image and whether her husband is still attracted to her following the accident, then CBT could be helpful. She may have some 'irrational' beliefs and thoughts about how she is seeing herself and how her husband now sees her. CBT may be a relatively straightforward way of helping her; it has a lot of face value as a therapy and she may notice change relatively quickly.

Disadvantages: This problem may be indicative of deeper fears she has, and the problem may be more complex than she is letting on. Farah's accident may have caused previous worries in her relationship to resurface; in this case CBT may not offer sustained help for her. Offering straightforward CBT to Farah does not involve her husband and does not suggest that they should be treated as a couple. In this instance there is a good argument for helping Farah to communicate some of

her fears with her husband. It is important you explore other possible reasons for this problem (pain, husband's fear of hurting his wife, disinterest in sex as a symptom of another disorder (for example, PTSD), fears and phobias associated with the accident).

3 What other psychological approaches might help Farah?

Listen to Farah's fears with a supportive, counselling approach with the aim that if she is able to express her fears this may help her to develop a strategy for coping and enable her to feel less isolated with her fears.

Normalising her fears – it is after all only six months since her accident.

Work in a joint way with Farah and her husband so that they can work together towards achieving a fulfilled intimate relationship. It would be important to ensure that Farah and her husband want to do this and see it as being relevant.

This case study suggests that Farah had a good relationship with her husband prior to the accident. Don't pathologise too much, but treat with a normalising approach and support, rather than overcomplicated therapy with a lady who still may be very vulnerable following her accident.

Your preferred approach will depend on the resources available at your service and the preferred therapeutic model of psycho-social staff, but this example should raise issues about how you can offer appropriate therapy to out-patients.

These points, and others, may have come up in your answers:

- 1** She would like help; however what would Farah like it for? Get a better understanding of her fears and worries. Have her feelings, actions and behaviours changed and if so, how?
- 2** How complex is this situation? Is it something that CBT would be useful for? Should a therapy also involve her husband?
- 3** Normalising fears, supportive counselling approach, help her to feel less isolated with her fears.



Case study 4 – Sadiyah

Sadiyah is 22. This is already her fifth admission to your burns service in the past two years. Staff believe her to use boiling water to self-harm her forearms. She has had numerous previous skin grafts, but her repeated re-injury is causing a breakdown, infection and increased scarring. The staff at your service are increasingly concerned and frustrated that each re-admission is detrimental to previous treatment. The specialist psycho-social team have tried to intervene during her previous admissions. When questioned, her family always say the injuries are accidental, that she is happy at home and constantly push for her to be discharged and cared for within their local Muslim community. After visiting hours, Sadiyah, who is normally very quiet, has confided in you that she is unhappy and told you how she injures herself.



Task

1 What concerns might staff have about treating repeat self-harmers? How might these be addressed?

As staff you are expected to treat everybody who comes into the ward the same and not to judge the way in which your patients receive their injuries. However, this can sometimes be very difficult as this case demonstrates. Some staff may find it hard if they feel that the good medical care and treatment that Sadiyah has received in the past is being undermined by deliberate behaviour. They may feel angry and, in the worst case, this may overflow into their treatment of Sadiyah and her family. It is important that staff remain professional and objective in their care of Sadiyah and her family but that these concerns are also acknowledged in a ‘safe’ forum.

1 There may be concerns about the repeated use of expensive NHS resources. Staff may express strong feelings about withdrawing treatment even though this is obviously not an option. There is however likely to be pressure on staff, Sadiyah and her family to ensure that her behaviour does not continue. However these are very delicate issues that are probably not quickly addressed and a confrontational approach may exacerbate the situation making it more difficult to work with Sadiyah and her family.

2 There may be concerns about discharging her whilst the underlying problem is unresolved and is therefore likely to happen again. The team may want to make recommendations about not discharging her so that there is more time to consider some of the psycho-social issues. This may even mean that if the family (and Sadiyah) insist upon discharge, it is made clear this is against medical advice.

3 Staff may want to think about the policies regarding the protection of vulnerable adults and whether they are relevant in this case.

4 As a senior staff member in the service, possibly with some responsibility for providing psycho-social care, you may want to think about how these issues are addressed with staff. A forum

(supervision, debrief, MDT or case discussion) for staff to express their concerns and frustration may be useful in this instance so that a consistent approach is achieved and staff's feelings are contained and do not affect the care of Sadiyah or any other patients in the service.

2 What issues does this case raise about confidentiality?

Sadiyah has confided in a member of staff and her confidentiality must be respected as there is no suggestion here that she does not have capacity. This has implications for the way in which you approach the family when their story conflicts with Sadiyah's own. It may have taken her some time to pluck up courage to disclose the way in which her wounds occurred and you need to maintain this trust to be able to talk to her again.

1 You might want to reflect with your staff team on how the staff member in whom Sadiyah confided responded to this. Do you have policies in place in your service about sharing such information with other staff and, if so, how did the staff member explain this to Sadiyah? There might be opportunity to encourage your tier 2 learners to go back to the 'What to say?' section. Reflecting as a staff team about how you manage this kind of disclosure with both staff and patients, and families may be useful.

2 It is important to keep the communication open with Sadiyah. There may be good reasons why she has chosen to confide in a particular staff member, although she needs help from a more specialist member of the team. How are you going to manage this? There may also be good reasons why the staff member she has chosen to confide in should continue to work with her, as she has clearly built up trust and may not want to disclose to another person. She may also become anxious if it seems like the issue is escalating out of her control.

3 Perhaps some initial work could be done with Sadiyah to encourage her to talk to a specialist staff member. The staff member that Sadiyah has confided in may need some support in how to do this.

4 It is essential that staff adopt a consistent approach with Sadiyah's family. Perhaps a specialist member of the psycho-social team (and someone not directly involved) might suggest a meeting with her family to try and hear a little more about their account of events, and hear their concerns. It is important that this staff member acknowledges their account at all times but gets more detail. For example, are there any causes or patterns they can suggest for Sadiyah's continued accidents such as unsteadiness, or the way in which the kitchen is arranged?

3 What ways might there be to break this cycle of self-harm? What else do you need to think about to do this?

At present you only have limited information about this case and you or the team will need to gain a better understanding of the factors that may be at play here. This will need careful counselling with Sadiyah, and discussion with her family as both will need to be assured of confidentiality, although ultimately you must act in the best interests of Sadiyah as your patient.

Be careful about making assumptions about the conflicting stories that are coming from Sadiyah and her family.

Do not assume that Sadiyah is self-harming. Is there the possibility of abuse which Sadiyah cannot disclose, or is fearful of disclosing?

1 Do not assume that Sadiyah wishes to return home with her family. Is her continued self-harm an indication that she needs help to deal with some of these family issues?

2 Perhaps Sadiyah's family are also covering up more complex aspects to this case. Do not assume that they too do not need help.

3 There may be cultural issues here. Perhaps either Sadiyah or her family are covering up major issues and problems because they do not want to lose face within their extended family or community. Perhaps Sadiyah's behaviour is seen as bringing shame upon the family. As a staff team you may want to seek advice or support from someone in the Muslim community who may be able to help understand these issues or work with the family.

What your goal is here and what you need to do to achieve this?

1 You will want to ensure that Sadiyah is discharged safely and that there is continued help for her and/or her family. To do this you will want to get more information. This is likely to involve discussions and counselling with both Sadiyah and her family, maybe separately at first and then together.

2 Ultimately your key aim might be to help Sadiyah and a member of her family to come together to discuss and resolve the issues. This may be a longer term process.

What ways might the team achieve this?

1 Offer Sadiyah continued support from someone who can see her at times when her family are not around.

2 Seek support and advice from someone from the Muslim community. This may be indirectly or to work directly with the family or Sadiyah.

3 Are there any Asian/Muslim counselling organisations to which you could refer Sadiyah?

4 It is fundamentally important to work with Sadiyah at all times, to keep her informed and get her consent about what you are doing.

These points, and others, may have come up in your answers:

- 1 Some staff members may find this difficult (use of NHS resources etc), concerns surrounding discharge, protection of vulnerable adults, the best way to address issues with staff – forum, discussions, clinical supervision?
- 2 Policies regarding sharing information? Keeping the communication open with Sadiyah, adopting a consistent approach with the family.
- 3 Currently acting on limited information, careful about making assumptions, family may also need help, are there cultural issues? Careful discharge planning.



Case study 5 – Frank

Frank is 42 and was injured in a gas explosion in a factory where he works. He received 45% mixed-depth burns and an inhalation injury. Frank has now been admitted to your service following a two week period in intensive care. He is likely to lose significant function in both hands, having lost the majority of his fingers. He will have extensive scarring to his upper body and face which will require further plastic surgery. Frank has a loving wife, three children (11, 7 and 3) and parents, who are all devastated by his injuries. They want to do everything they can to help with his rehabilitation.



Task

- 1 There are clearly many functional and psycho-social issues to consider during Frank's stay in hospital and after discharge. What are the key aspects to consider? How might staff cover these?

This case is likely to involve close MDT working and staff being clear about their role. They will have different answers and perspectives to this question depending on their role within the service, but most staff working at a tier 3 level are likely to have a role in supporting Frank and his family. Below are some suggestions that may be helpful working with this case.

Staff might look at one another's roles and ensure that Frank and his family's needs are covered in an efficient, empathetic and consistent way. Sometimes contact with too many people, all with slightly different roles, can be confusing and frustrating for families and this should be acknowledged.

1 Acute care: Frank may have confused memories of his time in the Intensive Care Unit. This could even have included experiencing psychotic symptoms (possibly as a result of drugs given to him on the unit) and sensory deprivation. He is likely to have had a tracheostomy which may have implications for his speech, communication and dietetics. Even now Frank is in rehabilitation there may be continuing effects as a result.

2 Functional: varied allied health professionals will be involved in Frank's rehabilitation in hospital and post discharge. It might be important for them to reflect on Frank's reaction to his injuries and how this

may change over time as this may not be a continuing upward process but more reflective of dips, plateaus and periods of better progress. This might influence how staff work with Frank as working with him to set and achieve goals may motivate him, and staff should acknowledge his need for space if required. It is important for staff to recognise this and to help Frank and his family to understand this too.

3 Financial: there may be financial implications for this family. Frank may not be able to return to his work for a significant period of time, if at all, and therefore the family may need help to look at and secure their future income. This is often a very sensitive subject for people especially if they have never required help before and it might be worth reflecting on how this issue can be approached sensitively. Timing might be important too, as discussing long term financial issues with Frank and his family requires an acknowledgement from them that things will not return to the 'normal' as they knew it. Sometimes it is important not to 'push' families until they are psychologically ready. Acknowledging difficult things like financial issues can highlight the different ways in which families are coping with the situation.

4 Spiritual: there is no mention of Frank's family's faith here. Severe injury and trauma can sometimes pull people closer to their faith or feel more distant from it and question it. Acknowledge this and offer faith support where appropriate. These feelings may well be in the context of the underlying psychology, and a chaplain or other faith leader can have an important contribution to an MDT team.

2 Frank has not yet seen his facial injuries; how might staff support Frank when looking in the mirror for the first time?

Looking at wounds, injuries and scars for the first time, and subsequently, can be a very difficult moment for patients. Looking in the mirror for the first time can be especially difficult. There is research to suggest that if these moments are handled well then the psychological 'recovery' can be better and that if handled badly the psychological recovery can be hindered.

Part of the key to this will be in the preparation.

1 Involving Frank from the earliest possible moment in dressing changes and wound care will help him psychologically to cope with his appearance during prolonged periods of treatment and as the scars settle. It will also help him to feel as though he has some control in an otherwise uncontrollable situation. It may also help him to find ways of integrating his changed appearance into his sense of 'self' as time goes on. He may not be physically able to do much, but encourage staff to explain and describe to Frank what they are doing and why.

2 Be realistic about setting expectations for Frank on the length of time improvement, treatment and recovery might take. This is often a difficult balance between being too optimistic and thus eventually

disappointing patients, and being too pessimistic or vague, leaving patients and families with less opportunity to make realistic goals for themselves. You might want to suggest Frank talks to someone who might be able to answer these kinds of questions.

3 The timing of looking in the mirror is important. If he is insistent, you will want to prepare him beforehand for what he will see and talk about how things will improve. If he seems to be avoiding, then it may take time and gentle encouragement before he is ready, but you will need to persist with this. Work with the MDT on finding the right moment. You need to handle the 'looking in the mirror' with care and there are some good tips for the staff team on page 31.

3 How might you involve and help Frank's family with his rehabilitation?

Frank's family will need to be involved as much as possible from an early stage. You know they are supportive and loving but the accident will have upset them too and remember that they too will be feeling many of the emotions and feelings described in module 3. This may be bewildering at first as it is Frank who is injured, not them. Reassure them that these kinds of reactions are normal and it is in no way a sign of 'weakness' or 'not coping', and that Frank too may be feeling strong emotions.

Frank has three children of varying ages and you may have to help Frank and his wife to give each child 'age appropriate' explanations for his injuries and the proposed treatment, whilst pointing out the importance of honesty. Research shows that children need to have an explanation, otherwise they can dream up fantasies for themselves about what happened which may be very different from the reality and increase their anxieties. If they don't understand now, they may have to find new explanations as they get older or fill in gaps in what is otherwise a difficult experience. Don't be too concerned if the younger children are more interested in the practicalities of life as "Who is going to take me to football?" and "How is daddy going to put his shoes on?" might be common questions. Parents can be worried if children seem not to feel things in the same way, but this is normal and everyone might need reassuring about this.

You will probably want to work with the family on how they can help Frank during a prolonged stay in hospital. There may be little things the children can do to help him continue to feel involved in their lives.

Once Frank is discharged there will be many ways in which the family need to be consulted and their involvement in decision making along the way will help them all to learn to cope with the new situation that this family will face.

These points, and others, may have come up in your answers:

- 1 Close MDT working including the key members of the family, any financial impact on the family.
- 2 Acknowledging this may be difficult, finding the right time, being realistic, answering questions honestly.
- 3 Involving the family from the earliest stage, reassuring the family and Frank, age appropriate explanations for his children, preparation for discharge to involve the family.



Reflection

Consider and review the current strategies in your service for providing psychological support to patients. Do you have ideas of what could be improved or amended? If you believe your service already provides comprehensive care, how could you disseminate this information to other burns services as a case study of good practice?

This will clearly depend on your service and its policies. Have the above case studies raised any issues that could offer opportunity for further learning? Has this resource pack raised issues of things that could be reviewed/improved/changed? Or has the management of other recent cases provided opportunity for reflection and learning?

If you feel there needs to be change in any area, what steps need to be taken to start to instigate this? Where are your key influencers/stakeholders? Who else do you need to involve?

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Notes

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