

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?

STUDENT MANUAL TIER 2



Why this training?

The purpose of this training is to ensure that all staff working in or with burns services in London and the South East gain appropriate knowledge of the psycho-social aspects of care for their job role. While hospitals provide a good level of physical care, a major review in 2001 suggested the psycho-social support provided for burns patients could be improved. Standards produced in 2008 aimed to secure this improvement in care. This training package is designed to promote, encourage and embed the National Burn Care Group standards for psycho-social care into the patient care pathway.

According to your job role within the unit, you will be allocated to either tier 1, 2 or 3 and will complete a training package dedicated to your tier. Prior to commencing this training, you should have agreed with your line manager which tier is appropriate for your role. This training package is designed to meet a variety of learning styles and throughout the course you will participate in reflection, a discussion of case studies and recap theoretical information. References are provided throughout the modules to provide further information on the topics covered. This course can be completed in a variety of ways from self-directed study to group training sessions. Your trainer will suggest the best way to complete this package for you and your team.

Throughout this manual you will see the following symbols:



Key information

These sections provide a discussion of some of the key theoretical information and knowledge relating to the key aims of the module.



Case study

These sections introduce a patient scenario. Each one is usually followed by some questions or a structured discussion on the issues raised. You can replace the case studies with your own if this is thought to be more appropriate.



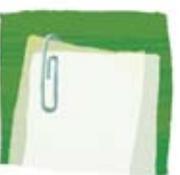
Task

These are tasks designed to encourage thinking and learning around the main teaching points. Optimal learning is achieved through active participation in these tasks.



Reflection

Learners are asked to reflect on their own experiences and patients they have worked with to encourage integration of their learning into their work. Although all reflection can be undertaken individually, learners will gain more from sharing experiences.



Further reading

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



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.

A large rectangular area with horizontal dashed lines, intended for drawing a diagram or writing down information.

What is psycho-social care?



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.



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.



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

Handwritten response area for 'The time of the accident'.

Being admitted to the ward and meeting all the staff

Handwritten response area for 'Being admitted to the ward and meeting all the staff'.

Seeing the doctor to discuss your treatment for the first time

Handwritten response area for 'Seeing the doctor to discuss your treatment for the first time'.

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

Handwritten response area for 'Seeing your friends and family for the first time at visiting time'.

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

scared for himself
useless – he won't visit his
colleagues at work
depressed
anxious
withdrawal – he won't go out
with his friends anymore

Society's feelings/behaviours

embarrassed – they don't know what to say
distressed
pity
they may stare and look
strangers ask difficult questions



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

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

Going back to manage the local Sunday football team

Going to wait at the school gates for his children

Doing the washing up

Returning to work



Communicating with patients

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



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?



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?

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.

A large rectangular area with a dashed border, intended for writing a response to the task.



Further information

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?

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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?

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Notes

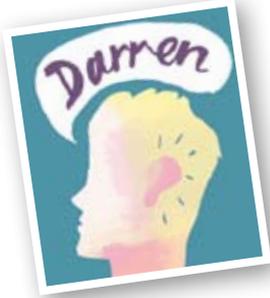
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Task – factors influencing positive coping

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

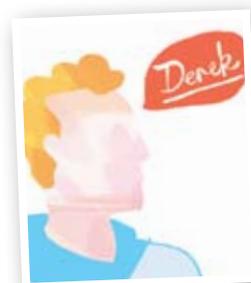
Jane has always worried what people think of her



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



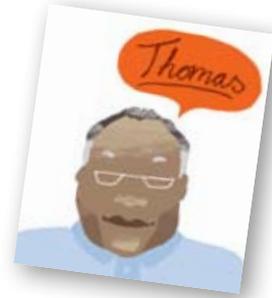
Percy is well respected by his peer group



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



Sarah left school at 14 and never did very well



Niraj's family says his scars can hardly be seen

Factors predicting positive coping



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



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

- 2 things to say if someone asks you what happened

- 1 thing to think if someone appears to turn away



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”

“I’m sure people won’t notice”

“Your scars will fade”

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

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.

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.

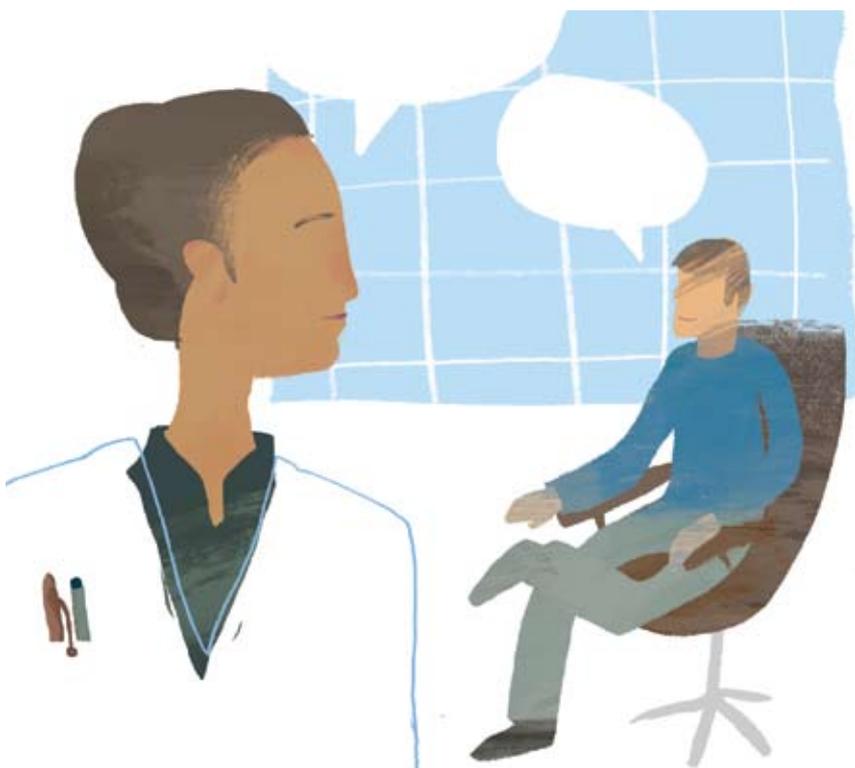
Top tips

- 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.



Further reading

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



Notes

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Notes

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