Part 2 – Psychological Care after Stroke
Psychological Care after Stroke

Introduction

The following section examines the emotional impact of stroke. The National Stroke Strategy (2007) recognises the central importance of a pathway that addresses the psychological changes that occur after a stroke. The National Institute for Health and Clinical Excellence (NICE) and the Royal College of Physicians’ (RCP) national guidelines recommend routine assessment and management of mood and cognition after stroke, whereupon assisting people with psychological issues following stroke is everyone’s role within a stroke team. The aim of this section is to provide information for all staff to help a person who has experienced a stroke in understanding their adjustment, assisting them with ‘normal’ adjustment to stroke, and support them with more serious mood problems that have reached clinical significance. Interventions on the most basic levels (Tier 1 and 2) of the Stepped Care Approach are discussed to make staff aware of how they can assist a person to optimize their well-being over the short and the longer term.

Learning objectives – Psychological care

Specifically the core competencies covered are:

- Understanding the person’s experience of the stroke and assisting them psychologically in the early stages (acute and early rehabilitation).
- Assisting with distress and adjustment post stroke, incorporating psychological models on adjustment to stroke and ways to help.
- Awareness of types of psychological problems following stroke
- Screening methods and tools to measure mood and other psychological problems, including reference to clinical guidelines for measurement of mood.
- Understanding and assisting with psychological problems after stroke: depression, anxiety problems, anger problems.
- Pathways for referral for more complex presentations
There are a number of psychological issues that can be experienced by our patients after stroke. Among others, these include:

- Depression
- Anxiety disorders (for example panic disorder, social anxiety, post-traumatic stress disorder)
- Emotionalism
- Adjustment disorder
- Anger problems
- Problems with social re-integration
- Family problems.

The National Institute for Clinical Excellence (NICE) advocates the *stepped care approach* for the identification and alleviation of mood issues following stroke. The aim is for the whole team to be skilled to understand and assist with alleviating psychological difficulties. A hierarchy of possible solutions to assist with mood issues guides how we support patients, beginning with the simpler solutions and reaching the more complex solutions as required. This can be seen in the tiered model and examples of approaches which may be used with patients below.

The importance of mood has been recognised by the Accelerating Stroke Improvement (ASI) programme: “mental health needs should have equal status with physical health problems following stroke”. Their guidelines for assisting with
psychological care state that all staff (not just specialist mental health staff) should spend time with patients exploring and supporting the impact of the stroke, as a part of their job.

Staff training and transparency about assessments, care plans and approaches used to help a person improve psychological issues faced is key to the effectiveness of our interventions.

Part 2 of this manual deals with adjustment, depression, anxiety and anger.
Adjustment

Distress and Adjustment

Stroke is a sudden and unexpected event for which a person is generally unprepared. Apart from cognitive and physical changes, the person also has to contend with hospital procedures, which is demonstrated by patients' accounts of having a stroke. A Patients experience:

Case study 1: Linda

Linda “I arrived at work and was taking off my jacket, I turned around to speak to a colleague, and nothing would come out. I tried again and I thought well that’s funny. I’ve got a false tooth and I thought it had fallen out, and the more I was trying the more frustrated I was getting.

I became very distressed and I was also embarrassed because I thought, I am the manager of the centre and I’m a quivering wreck. I thought I need to go to the toilet and I went to the toilet knowing I wasn’t right.

The receptionist made me a cup of tea and said “I think you should see the doctor” and I nodded o.k. My senior worker was due to start later on that morning and so I thought I’ll hold the fort and see what the doctor says, I went to pick up the cup of tea and when I tried to drink the tea, it all just went down the side of my mouth. One of the senior carers happened to appear and said “she’s not going to any doctor, we’ll get her into the car and take her straight to the hospital”. I didn’t even argue with her.

I don’t remember the journey from the centre. I do remember as I came out the office there were two or three of the staff totally shocked because they obviously didn’t know what was going on, but were concerned for what was happening. I do remember walking into the hospital and some of my speech was coming back and then it would go away again. They took me through into one of the booths in casualty and I started feeling much better, and I started to be able to speak again.

They hooked me up to the monitors as their initial thoughts were that it was possibly a virus that I had. At this point I thought, why am I sitting here,
there’s nothing wrong with me, but the side of my face was a bit twisted and then I said “I need to go to the toilet” and the nurse said “just a minute and I’ll get you a chair”, I said “no I’ll walk”, I went to get off the bed and I couldn’t, the left side of my body just wouldn’t move, I was worried I had a brain haemorrhage, because that’s what my mum had died of. I was only 29 when she died, and one of the biggest fears I’ve lived with was the same thing happening to me, even though I have never suffered from blood pressure problems.

I didn’t want my dad to get all worried about it and I knew John (my partner) was in London, so I wanted it all played down and I didn’t want my girls worried about it either.

Following a CT scan, the doctor came to speak to me and was very, very good and explained why the cat scan hadn’t shown anything, but that didn’t mean that there wasn’t anything wrong, he went through it in great detail, then spoke about how they would admit me and would continue observations.

By this time it was about 6.00pm and John had arrived at the hospital, I was obviously worried and emotional, but was shocked when a nurse and a porter came to move me up to the ward and said “we are going to take you straight up, we’re quite confident that you have had a stroke,” that was the first actual mention of the word stroke. It appears that there was a miscommunication between the nursing staff, as they had assumed that the doctor had told me that I had suffered a stroke.

That first night was horrific, absolutely horrific very scared wondering what was going to happen next. There was a bit of me that still kept thinking, “no it was a mistake I’m fine, I’m going to be alright” but my left hand was getting worse and I kept trying to move it, kept on rubbing at it and trying to get it to do something. The following morning and later on that day people came to visit me, they all seemed to be in tears, I thought I must be going to die, they’re all in tears, everybody that comes in is in tears, and people were flooding to see me – I had that kind of scared feeling and then thinking to myself, are they telling me the truth, do they know something that I don’t?
John was an absolute marvel. He was there, he was strong, he was really good and he didn't break down or anything in front of me, he kept strong and he kept saying well this is it, this is the way it is, we are in this together, but I started thinking why is he saddled with me, this crippled person?

It was very difficult to accept that I could look and see the left hand side of my body, but it had no sensation or feeling, and I could not move any part of it. Everyone was telling me that things will improve, but you don't know whether they're just saying that, or it really is going to get better? I was wondering how was I going to manage, and how was I going to be able to be there for the girls. What was this all going to mean, it was scary. There’s nothing else that can describe it, just being afraid, afraid of what was ahead. What springs into your mind is work as well, how was I going to be able to support myself and work, and who was going to be there for me”
The main aim in helping people who have experienced a stroke is to be person centred, right from the admission to the end of the stroke rehabilitation journey. Suggestions for ways to help in the acute stage of stroke are included in the box below:

- Efficient and speedy response to the medical emergency
- A thorough investigation
- To be talked through tests and given reassurance
- To be treated with respect
- To be kept informed and given explanations about what is happening
- To be treated with consideration, and the same for their family
- To have staff be proactive in helping a person, Quote “you just want some action when you are not feeling well”
- For staff to be informed about their diagnosis and to all be working from the same information
- For staff to understand how difficult it is for the patient and the family at this time and to support them and listen to their feelings and their needs.

As described in the case of Linda, the person experiencing a stroke is often in a state of shock. They will have to go through a number of tests and procedures and contend with a busy hospital environment. In addition, people who have experienced a stroke may be facing any of the following issues:

- Weakness affecting one side of the body.
- Mobility/ movement problems
- Visual difficulties.
- Incontinence - having to ask to be taken to the toilet.
- Cognitive problems, including limited or patchy memory of
the stroke itself.

- Difficulties with speech: understanding what is being said, difficulties getting words out, difficulties reading and or writing.
- Temporary loss of role/ control/ identity
- Fatigue
- Loss of independence/ dignity

It is no surprise that many people who have suffered a stroke will experience a range of emotions regarding what has, and what is, happening to them including fear, distress, embarrassment, anxiety, and disorientation. Many people miss their family members and find a new environment difficult to cope with.

Listening to a person’s psychological issues right from the start, and throughout their journey of recovery is crucial. Our aim as health professionals is to try and understand each person’s experience of having the stroke including the impact it has had on their life, and their emotions and challenges faced at every juncture. Our support can make an enormous difference to how people feel, as the quote of a person who experienced a stroke highlights here:

“You realise (in my case in hospital) what’s happened, you are still scared, but now other emotions come into play; anger, sadness, depression, low self-esteem, just to mention a few. To be able to try to express your feelings to someone who appears to understand, is in my opinion vital to the recovery process”.

Consider the exercise on the following page, thinking of a time when you received care from a health professional and reflecting on what they did to help you. Think about how you deliver care and what may help you to deliver even better care.
Reflective Exercise:

- Reflect about a time when you or a relative stayed in hospital or had an appointment.
- Think of the staff who were there to help you. Write down the characteristics or behaviours of staff that helped or did not help you.
- Reflect on how the environment affected how you felt as a person in this time.
- Jot down any thoughts on how your characteristics or behaviours may help or not help a patient in hospital. Is there anything that you could improve upon?
- How could you change or improve the ward environment which may help to understand an individual better, or make them feel more individually understood?

Further suggestions to help the person throughout their recovery process are included in below: *(you can also find a ‘Dealing with Distress Worksheet’ in the toolkit)*:

- Show people respect and dignity at every interaction; treat others how you would like to be treated;
- Assess their individual needs, likes/dislikes. Devising a personal profile can be valuable. See the toolbox for various profiles;
- Help people to understand what is happening to them, including how the ward/team is run and routines;
- Ask if people have worries or concerns. Is there anything a person deems very important? Specifically, is there anything they are worried about? Assist the patient to problem solve what they are worried about, e.g. a patient may be worried if the dog is being cared for;
- Be aware of a patient’s self-image/confidence issues: can we help here? How a person likes to be dressed, or have their hair done (family members can often help with this);
- Where possible allow choices in the day to help the person regain a sense of control. For example, help the patient following some hobbies/interests, to feel that they have a purpose in the day;
• Invite people to tell you what has been happening to them, to tell their “stroke story”. This helps people to begin to emotionally process the stroke, and how they are feeling;
• Normalise the adjustment process after stroke; Give feedback, encouragement and show kindness;
• Give information to match their needs. Research has suggested that providing information in a way that actively involves people with stroke and their carers has a positive effect on the patient’s mood;
• Give family support when possible.

Understanding distress

Most of us go through life with an “it’ll never happen to me” attitude. This is a belief that we are relatively invulnerable, and it protects us from worrying about every bad thing that could possibly happen to us. After a stroke, many people lose this belief, and instead experience constant worry that something could, or will, happen to them (their belief has changed from invulnerability to vulnerability) – they have faced their own vulnerability/mortality and this is something that they cannot quickly forget.

Many stroke sufferers consider the question “why me?” in an attempt to understand this life-changing event. This is particularly the case where the stroke affects younger adults, or those who live a healthy lifestyle. In these circumstances it can be very difficult for someone to accept the fact that they have had a stroke, and even more so if a cause or reason for it is not obvious.

It is normal that most people will experience a psychological reaction such as shock, grief, anxiety or depression to the stroke. However, every stroke is different, and every individual is different. We sometimes encounter patients with a major stroke who adjust very well, while others experience great distress at what we consider to be a minor stroke. Therefore, we aim to try and understand what it is like for a patient to have had their stroke, what it means to them and what strategies they can use to try and cope.
Depending on the severity of the stroke, an individual may experience loss for many things – loss of physical health, cognitive abilities, independence etc. The table below illustrates the dimensions of loss.

<table>
<thead>
<tr>
<th>physical health</th>
<th>cognitive ability</th>
<th>self</th>
<th>financially</th>
<th>future</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Loss of speech</td>
<td>• Memory loss</td>
<td>• Loss of dignity</td>
<td>• Loss of job</td>
<td>• Loss of dreams</td>
</tr>
<tr>
<td>• Loss of mobility</td>
<td>• Loss of decision making</td>
<td>• Loss of identity</td>
<td>• Loss of income</td>
<td>• Loss of future goals</td>
</tr>
<tr>
<td>• Loss of energy</td>
<td>• Loss of concentration</td>
<td>• Loss of role</td>
<td>• Loss of security</td>
<td>• Loss of independence</td>
</tr>
<tr>
<td>• Loss of libido</td>
<td>• Loss of control</td>
<td>• Loss of sense of purpose</td>
<td>• Loss of control</td>
<td>• Loss of control</td>
</tr>
<tr>
<td>• Loss of control</td>
<td></td>
<td>• Loss of respect</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Earlier we talked about how most of us go through life with an “it will never happen to me”-attitude. After a stroke, many people will be uncertain and even expect things to go wrong. The above table illustrates that many people experience an overarching feeling of loss of control.

Accepting a stroke and accepting that life may be very different from that point forward is difficult but helps with recovery, both physically and emotionally. The following section explains models of adjustment.

**Models of Adjustment**

Models exist to help us to understand the emotional impact of the stroke and the adjustment process for the patient and their family. We can share these models with people to help them to understand what is happening for them.

**Stage Models of Adjustment:**

One way of looking at coming to terms with a stroke is to liken the emotional adjustment to stroke as being similar to the process of grieving following bereavement. Wilkinson (1995) suggested that patients may go through a number of stages, which include:
The model suggests that people “emotionally process” and make sense of the stroke by going through the stages. Within each stage people may have a number of feelings, thoughts, behaviours and physiological responses. They may go through a grieving process for the life they had before, and the activities and experiences which they may no longer be able to have. Not everyone will go through the stages in sequence, and some will stay in one stage for a long time, e.g. anger.

There is no right or wrong way to adjust. We can help by identifying where the person is at and talking through the process of grief and loss to normalise the experience. In time we hope that many will rebuild their life, even if it is a different life. We often explain this process of adjustment as being two sides of a coin; grieving for what we have lost and rebuilding what we can.

**The several stages of grief (as applied to stroke)**

![Stages of Grief Diagram](image)

Another useful model about processing grief is provided by Stroebe and Schut (1995,1999). They developed a Dual Process model of grief, aimed at bereavement counselling. They acknowledged that avoiding grief is not always detrimental, but can be helpful to the person if it helps them to control their emotions. Therefore the person experiencing grief may alternate between focussing on loss (loss orientation) and avoiding loss (restoration orientation). The focus on loss here will allow the person to process their grief, while the restoration focus involves taking time off from
the grieving process in order avoid becoming overwhelmed and dealing with the secondary losses, such as accepting new roles etc.

In the context of stroke, this may mean allowing a person to grieve for what the stroke has taken away from them and give them time to process this, but also allow them to explore what life will be like now. Therefore, avoidance is not always negative, and may give the person the strength to carry on.

Of course it is not only stroke survivors themselves who will experience loss and grief after stroke. **Family and friends** will also naturally experience feelings of loss for the changes that they have seen in their loved one, and they may even feel guilty for experiencing these feelings of loss. Unfortunately, in these circumstances they may be unable to share their thoughts and feelings with the stroke survivor which can hinder their own progress through the stages of grief, and delay them coming to terms with and accepting the consequences of the stroke.

As part of your role, you will be providing **support** to friends and family, as well as the patient themselves. Sometimes it is helpful to discuss concerns with a person outside the family who can look at the situation from a different perspective. **Signposting** to carer organisations in the longer term can help greatly.

Another model looking at adjustment after stroke that helps us to understand how people differ in their reactions to stroke was proposed by Twining (1988). Here, the experience of emotional adjustment to stroke is considered as the interaction
between the person and the handicap. Twining argues that this helps us to look at how different people adjust. In this model, we should find out about the person’s personality (e.g. sociable, not so sociable), interests (indoor hobbies, outdoor pursuits) and social networks in addition to the consequences of the stroke (see table below).

<table>
<thead>
<tr>
<th>The Individual</th>
<th>The consequences of stroke</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personality</td>
<td>Severity</td>
</tr>
<tr>
<td>Attitudes</td>
<td>Extent</td>
</tr>
<tr>
<td>Relationships</td>
<td>History</td>
</tr>
<tr>
<td>Interests</td>
<td>Cause</td>
</tr>
<tr>
<td>Activities</td>
<td>Prognosis</td>
</tr>
<tr>
<td>Expectations</td>
<td></td>
</tr>
</tbody>
</table>

The message this model provides us with is that a person who has a great social network but not many outdoor interests may do better after a stroke that is impacting on his mobility than a person who primarily likes hiking on their own.

A further model was proposed by Skelly (2002), who suggests that the meaning that people attach to the stroke affects how they adjust. Individual assumptions about their health, themselves and others can change following stroke. We all differ in how we react to events and also in what needs are important to be met in our life.

Consider Chris, who was only 40 when he had his stroke. While he made a reasonable recovery, he is aware that he can no longer play football with his son. This has always been very important to him, and now he thinks he cannot be a proper dad anymore.

**Adjustment – How we help**

The following tips may be helpful to support patients with their adjustment to their stroke:
**Talk about it**

When someone is admitted to hospital following a stroke, the immediate focus is on getting them better (physically) and getting them home. However, it is also important to take the time to get to know the patient, their goals and motivation and what is most important or difficult for them. Person centred profiles can be very helpful to get a better idea of who the person is - see the toolkit for some examples.

We also want to know how the person is coping. Talk to them about how they are feeling. This is crucial especially when they show distress. A helpful question here may be: “I noticed that you were feeling very emotional just then, I wonder what was going through your mind?”. Use the active listening skills described in Part 1 of this manual to support this.

**Expression of Grief**

Grief is very individual, and patients should be allowed to deal with it in their own personal way. Some people will cry, or shout or talk and ask a lot of questions, others will be very quiet and withdrawn and thoughtful. Some will want to be surrounded by friends and family, and others will want to be left alone. All of this is normal.

However, should the distress go on for longer than expected and be interfering with rehabilitation goals, you may want to consider a referral to a Clinical Psychologist (if available in your Trust) or a mental health team. It is worth carrying out some work with your patient in the meantime to try some of the strategies in the toolbox for use with low mood and depression – problem solving can often work well to show a patient that there are ways to achieve what is important to them. It can also break down the steps of how to get to where they want to be when everything seems overwhelming.

**Reassurance without minimising**

For most stroke survivors, it will be helpful to hear that the majority of people experience grief and loss after stroke. Generally, we like to feel as though our feelings and behaviours are “normal” and that there are others who know what we are
going through. However, normalising is not about playing down what has happened to someone. You do not want to minimise their experience – you are simply trying to help them understand that their reaction to the stroke is normal, and that other stroke survivors experience similar reactions. For example, if someone has a partial loss of speech, do not act as though they are lucky because some people completely lose their speech after stroke. Being told that there are others worse off rarely makes anyone feel any better – in fact it tends to just make you feel guilty for feeling so down about your own problems!

**Avoid telling people what to do**

When someone is feeling very low, it can be tempting to tell them that they ‘should’ start to accept what has happened, or that they ‘have to’ start engaging in therapy. Unfortunately, telling people what to do rarely works, and might lead to them doing the opposite. Instead, try the Motivational Interviewing techniques as described in Part 1. They allow you to encourage people to take action by supporting them to come up with ideas of what they should or could be doing to help themselves.

**Goal Setting**

This is defined as the process during which a patient and members of the multidisciplinary team collaborate to set goals based on the person’s values, needs and expectations. Patient centred goal setting can have a positive impact on psychological outcomes. The benefits of goal setting include improved self-efficacy, a sense of control and autonomy over their own life, self-assurance, reduced anxiety and empowerment. This can lead to greater participation in rehabilitation. It is important to set short-term achievable goals in addition to long-term goals to ensure the person experiences success and therefore motivation during their rehabilitation.

You can find Goal Setting worksheets in the toolkit, including completed examples.

**Utilise past coping skills**

Although most people who have had a stroke will not ordinarily have experienced anything quite as life changing and dramatic in the past, all of us have at times had to
adjust to change or to negative events in our lives. We all have our own way of coping with these things, and what works for one person might not work for another. Encourage patients to think about a time when they have endured a big change, or when they have overcome challenges or times of adversity, and the types of strategies they used to get through it.

Maximise people’s opportunities to cope

Try thinking about the things that you like doing. What do you need from other people when you are feeling low or facing stress/worry in your life? We all use different things when we are stressed. Perhaps you turn to exercise, meet friends, go for a long walk by yourself, or you indulge in shopping or a glass of wine. All of the above are coping skills we use to pick us up when we are down.

In the ward environment, people are limited to what they can actually do. Even when someone has been discharged, their impaired mobility might stop them from using their favoured coping mechanism. Ask the person what normally helps them, and be creative in recreating that. It can help the person feeling more in control of their life.

Encourage socialisation

Earlier, we learnt that getting the person to talk to us can help us getting to know them and support their adjustment. However, whether in hospital or in the community, talking to others in a similar situation and learning how they manage can be very helpful. Being part of social activities can help the person return to a normal routine.

Activities

Patients often spend a lot of time between their therapy sessions without activity. This can make the stay in hospital monotonous and might lead to low mood, e.g. when the person ponders their lack of progress, or worries about all the things they will not be able to do when discharged.

In order to break this routine, playing a game, or taking a patient off the ward for a drink and a chat can be very therapeutic. For
example, trips off the ward each week can give the patient something to look forward to and therefore help their mood. This could be organised by volunteers and family members. However, it is equally important that staff caring for a person on a day-to-day basis can take some time out to do an activity with them. This can help to build rapport and trust and develop the relationship between patient and health professional. Talk to the patient about what kind of activities they liked to do before their stroke and find out if there is a way of bringing that activity to them while they are in hospital. Group sessions in the day room can also be great for this – crafts, games, watching a film etc. can all help to improve the overall experience of being on a hospital ward for a long period of time.

**Summary**

There is an acknowledged emotional impact following a stroke. It is useful to help patients and their families to understand this and to encourage them to share how they are feeling. Our interaction with patients should be person centred, as different people have different coping mechanisms, worries, and strengths. Listen out for what people are distressed about; this can allow us to offer support, guidance, clarifying information, an alternative perspective, or problem solving. Using positive attachments with the person and providing activities outside the therapeutic interaction are also very important in the rehabilitation process.
Depression

Along with helping people work through the “adjustment process” following a stroke, our role as health professionals is to assist with the identification of people who may be suffering more distressing psychological reactions. Many of our patients will suffer from clinical depression or anxiety; this needs to be managed and treated as it can negatively impact upon the recovery process and overall outcome.

Imagine you had a very long day at work, due to staff sickness you cannot take the days off you had planned, and a patient you really care about has had another stroke. What do you experience?

You might feel a little down. You probably feel tired, and decide not to go to the gym as planned. You don’t enjoy your dinner as much, and when a friend rings to invite you out, you cannot be bothered. Instead you just sit and watch TV, but the program does not cheer you up. You go to bed early, but cannot really settle to sleep, so you have a restless night. The next day, you are exhausted, a little grumpy, and you are less motivated to throw yourself into the day.

Understanding patients’ experience

“Psychological problems” and “depression” are terms that we easily use without sometimes thinking of the experience of the individual. However, it is important to consider what the person is feeling when they have underlying psychological problems.

Depression is quite common in the general population. Each year, about one in 16 will be diagnosed with depression. However, when we consider people who have two or more chronic physical health problems, nearly one in four (23%) suffer from depression.

For those who have had a stroke, figures vary depending when you ask people (acute, rehab, community), though as many as one in three patients experience depression at some point! Therefore, it is not surprising that depression is considered the most frequent psychological consequence of stroke.
This is important because there is a strong relationship between psychological problems and recovery. Depressed stroke patients often lack the motivation to engage in the rehabilitation process, make less progress in recovery, have longer hospital stays, and do not engage in leisure and social activities.

This also impacts on long-term outcome: research has shown that depression at 1 month predicts mortality at 12 months after stroke, and that persistent psychological symptoms in the first 6 months after stroke are associated with substantially poorer physical function outcomes at one year. It is therefore important to identify and treat depression in order to improve outcomes for patients and their families.

**What is Depression?**

Depression is the fourth leading cause of disability and disease worldwide. It can sometimes be difficult to discriminate it from poor adjustment. Depression is diagnosed when low mood and a deterioration in people’s functioning lasts for weeks rather than days and significantly affects an individual’s well-being. Below are the diagnostic criteria for depression:
Table 1: DSM IV-TR criteria for major depressive episode

<table>
<thead>
<tr>
<th>The DSM IV-TR criteria for a Major Depressive Episode are:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Five (or more) of the following symptoms have been present during the same 2-week period and represent a change from previous functioning. At least one on the symptoms is (1) depressed mood or (2) loss of interest of pleasure</td>
</tr>
<tr>
<td>-----------------------------------------------------------</td>
</tr>
<tr>
<td>• Depressed mood</td>
</tr>
<tr>
<td>• Markedly diminished interest or pleasure</td>
</tr>
<tr>
<td>• Weight loss or weight gain, or marked change in appetite</td>
</tr>
<tr>
<td>• Insomnia or hypersomnia</td>
</tr>
<tr>
<td>• Agitation or retardation</td>
</tr>
<tr>
<td>• Fatigue of loss of energy</td>
</tr>
<tr>
<td>• Worthless or guilt</td>
</tr>
<tr>
<td>• Poor concentration or indecisiveness</td>
</tr>
<tr>
<td>• Thoughts of death or suicidal thinking</td>
</tr>
</tbody>
</table>

Some people may have suffered from depression prior to their stroke, as it is so prevalent in the general population. Therefore the term post-stroke depression does not always fit with these patients. Looking out for whether people have had episodes of depression prior to stroke is a very important question.

The example mentioned earlier may give you an idea how we all can feel when we are having a bad day. Depression can be considered on a scale form mild to severe. Now let us consider John, who provided the following quote:

“For me, it feels like I'm just stuck. It feels like a big black hole has been placed into my life, and everything that did or would make me feel better is just sucked into it. And there's this blanket of hopelessness that covers me all the time, thoughts that I'm not good enough, I'll never do anything right or that I will never succeed in life. Also that now I have had the stroke I am a burden and that my wife and family would be better off without me.

I think that I wish I wasn’t here, that the stroke had taken me but I keep trying, more for others than myself. Every day I wake feeling terrible and every night I feel lonely and tired. I can’t think of the future as I can’t even cope with the present. I only hope I can get better than this".
This description gives us an insight into a person who is experiencing severe depression. John’s symptoms are psychological (feeling low) and also physical and social. This may sound overwhelming, and it might explain why people find it hard to just ‘pull themselves together’. The table below highlights the different dimensions of depression we need to look out for:

**Table 2: Dimensions of depression**

<table>
<thead>
<tr>
<th>Psychological symptoms</th>
<th>Physical symptoms</th>
<th>Social symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>• continuous low mood or sadness</td>
<td>• moving or speaking more slowly than usual</td>
<td>• taking part in fewer social activities and avoiding contact with friends</td>
</tr>
<tr>
<td>• feeling hopeless and helpless</td>
<td>• change in appetite or weight (usually decreased, but sometimes increased)</td>
<td>• having reduced interest in hobbies and activities</td>
</tr>
<tr>
<td>• having low self-esteem</td>
<td>• constipation</td>
<td>• withdrawing from relationships and social interactions</td>
</tr>
<tr>
<td>• feeling tearful</td>
<td>• unexplained aches and pains</td>
<td></td>
</tr>
<tr>
<td>• feeling guilt-ridden</td>
<td>• lack of energy or lack of interest in sex</td>
<td></td>
</tr>
<tr>
<td>• feeling irritable and intolerant of others</td>
<td>• changes to your menstrual cycle</td>
<td></td>
</tr>
<tr>
<td>• having no motivation or interest in things</td>
<td>• disturbed sleep (for example, finding it hard to fall asleep at night or waking up very early in the morning)</td>
<td></td>
</tr>
<tr>
<td>• finding it difficult to make decisions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• not getting any enjoyment out of life</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• having suicidal thoughts or thoughts of harming yourself</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• feeling anxious or worried</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

As the quote from John demonstrates, people who are experiencing depressive symptoms will respond to day-to-day events in a variety of ways. They will have changes to their feelings, their physiological responses, and often experience negative, automatic patterns of thinking. See the toolkit for information about Unhelpful Thinking Habits. They also may change their behaviour when responding to things, for example by avoiding situations.
Research has shown that people who become depressed are thinking in a particular way: they think of themselves as *worthless*; the world is generally seen as *hostile* and rejecting and the future as *hopeless*, as something that only will get worse.

**Assessment**

The NICE Stroke Quality Standard (2010) set out that ‘*All patients after stroke are screened within 6 weeks of diagnosis, using a validated tool, to identify mood disturbance and cognitive impairment*’. The RCP further suggests that we should keep the patient’s mood under review. Therefore, when assessing mood, we aim to:

1. Identify those with a potential problem, e.g. using screening measures, often carried out by staff such as nurses, OT’s;
2. Gain an understanding of the nature of the mood problem in order to plan treatment. For this we need to determine the severity of the problem;
3. Monitor change in mood over time.

A good starting point is always to ask the person how they are feeling within themselves and how they think they are coping with what has happened to them. A number of patients will be quite open about feeling low, while others find it hard to open up or do not recognise what they are going through. Speaking to family members regarding their views on someone’s mood can also be invaluable. Family and friends may help us to “benchmark” someone’s mood – how is the patient normally? Are they any different now? They may also help provide clues as to why a person may be low, and what the important thoughts and feelings that a person may be experiencing may be.
Screening tools can help us to begin to identify whether depression may be a problem for an individual. As with any assessment used we should explain the purpose of the assessment to the patient, seek their consent to ask the questions and explain why it might be useful to them. This is an opportunity to normalise the fact that many people will feel low after a big life event such as a stroke. This may help them to open up.

A table of screening tools for depression developed by Burton et al (2011) is shown on the following page. The choice of tool will depend on the service.

**Table 3: Screening tool for depression for those without communication problems**

<table>
<thead>
<tr>
<th>Tool</th>
<th>Has the validity of the tool been tested with stroke patients?</th>
<th>Is the tool free to use?</th>
<th>Has the tool been demonstrated to be consistently sensitive and specific?</th>
<th>Can the tool be completed in &lt; 5 minutes?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beck Depression Inventory II (BDI II)</td>
<td>✓</td>
<td>✗</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>General Health Questionnaire – 28 (GHQ-28)</td>
<td>✓</td>
<td>✗</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Geriatric Depression Scale (GDS)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✗</td>
</tr>
<tr>
<td>Geriatric Depression Scale 15-items (GDS-15)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Hospital Anxiety and Depression Scale (HADS)</td>
<td>✓</td>
<td>✗</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Patient Health Questionnaire 9 (PHQ-9)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Wimbledon 10</td>
<td>✗</td>
<td>✓</td>
<td>✗</td>
<td>✓</td>
</tr>
<tr>
<td>Yale Question</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>

For people with communication difficulties the tools available are outlined on the following page.
### Table 4: Screening tool for depression for those with aphasia

<table>
<thead>
<tr>
<th>Tool</th>
<th>Has the validity of the tool been tested with stroke patients?</th>
<th>Is the tool, free to use?</th>
<th>Has the tool been demonstrated to be consistently sensitive and specific?</th>
<th>Can the tool be completed in &lt; 5 minutes?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stroke Aphasic Depression Questionnaire Hospital 10 (SAD-Q H10)</td>
<td>🍀</td>
<td>🍀</td>
<td>☑</td>
<td>☑</td>
</tr>
<tr>
<td>Depression Intensity Scale Circles (DISCS)</td>
<td>🍀</td>
<td>☑</td>
<td>☒</td>
<td>☑</td>
</tr>
<tr>
<td>Signs of Depression Scale (SODs)</td>
<td>🍀</td>
<td>☑</td>
<td>☒</td>
<td>☑</td>
</tr>
<tr>
<td>Visual Analogue Self Esteem Scale (VASES)</td>
<td>🍀</td>
<td>☒</td>
<td>☒</td>
<td>☑</td>
</tr>
<tr>
<td>Visual Analogue Mood Scales (VAMS)</td>
<td>🍀</td>
<td>☒</td>
<td>☒</td>
<td>☑</td>
</tr>
<tr>
<td>Distress Thermometer</td>
<td>☒</td>
<td>☑</td>
<td>☒</td>
<td>☑</td>
</tr>
</tbody>
</table>

See the following page for an example of how to use a screening tool - the DISCS tool Turner-Stokes et al (2005):
**Depression Intensity Scale Circles (DISCS)**

The DISCS is a mood screening tool designed for use with patients that have suffered a brain injury, for example after stroke. The DISCS screening tool can be seen below (this is the standard version, there is also a pictorial version for patients with some degree of dysphasia/aphasia).

The tool is displayed on a laminated card (you can find one of these in the toolkit) and the patient is asked to point to each of the circles individually to ensure that they are able to see them all. If the patient accomplishes this, you can then go on to explain what the different circles mean. The circles basically show how depressed an individual is, from no depression at the bottom of the scale, to depression which is as bad as it can possibly be at the top of the scale.

Point to each individual circle in ascending order (from no depression to most severe depression) and explain that as you go from the bottom to the top, the depression (or sadness) is becoming more and more severe. Finally, ask the patient which of the circles shows how depressed they feel today?

After the DISCS screening tool has been completed with the patient, there is a question for the administrator of the tool (you!) which asks if in your opinion the person was able to understand the scale. There is also space for any comments, so
for example you can note down if you are not sure of the patient's comprehension of the scale, or you can comment if the patient was undecided between two of the circles on the scale, or if they indicated anything in particular that was affecting their mood.

One of the best things about this screening tool is that it is very straightforward and quick to complete. It is also very visual, and does not feel like a test when you are completing it (which can help to alleviate anxiety that is often felt when patients are asked to answer questions/fill out screening tools). Although the tool is very simple and visual, it can be used with patients who do not have aphasia too, and indeed is often useful to use with patients who have cognitive impairments such as memory problems. For individuals with memory problems, it can be a big ask for them to remember several different responses to a question, so having something like the DISCS in front of them can be very beneficial.

The DISCS can be administered by any healthcare professional and the scoring of the tool is as straightforward as the administration of it. The bottom circle is scored as 0 (no depression) and other circles are scored from 1-5, with 5 being the most severe depression.

As with all of the screening tools mentioned in this manual, clinical judgement needs to be used alongside them. A one off score of 2-3 on the DISCS would not necessarily indicate that an individual requires treatment for low mood or depression – it could just be that they are having a bad day (remember that you are asking the individual to point to the circle which shows how they feel TODAY). However, consistent scores of 2 or above, along with clinical signs of low mood or depression would obviously be cause for concern. Depending on the severity of the mood problem, and the rating on the DISCS, you could use some of the strategies and self-management techniques mentioned in this manual, or if you feel that it is a more severe case and you need additional input, you could consider a referral to Clinical Psychology or Psychiatry services.

You can find a copy of a number of screening tools in the toolkit.
Where mood is identified as a problem (generally in the categories of mild, moderate or severe depression determined by the score) further assessment by interview should be carried out. Below is a flowchart of the NICE guidelines 90 and 91 - Identifying people with depression. It also introduces the concept of suicidal ideas and plans to harm oneself. Life problems outside stroke, emotions in significant others, and support structures are also deemed important as these too can affect mood and coping.

**Flow Chart 1: Nice Guidelines for long term conditions**

Be alert to possible depression (particularly in people with a past history of depression or a chronic physical health problem with associated functional impairment) and consider asking:

During the last month, have you often been bothered by:
- feeling down, depressed or hopeless?
- having little interest or pleasure in doing things?

If the person answers ‘yes’ to either question

A practitioner who is competent in mental health assessment should:
- review the person’s mental state and associated functional, interpersonal and social difficulties
- consider using a validated measure for symptoms, functions and/or disability
- for people with language or communication difficulties, consider using the Distress Thermometer and/or asking a family member or carer about symptoms; if significant distress is identified, investigate further

A practitioner who is not competent in mental health assessment should:
- refer the person to an appropriate professional – if this is not the person’s GP, inform the GP

If the person also has a chronic physical health problem:
- ask three further questions to improve the accuracy of the assessment:
  - feelings of worthlessness?
  - poor concentration?
  - thoughts of death?
- consider the role of the physical health problem and any prescribed medication in the depression
- check that the optimal treatment for the physical health problem is being provided and adhered to; seek specialist advice if necessary.

From the screening and further assessment of mood, a Mood Management Plan should be put in place for those identified with depression. Regular reviews should also take place - with the individual involved where possible. This ensures that we not only monitor mood, but also find out whether the Mood Management Plan is effective. Remember: Screening alone does not change anybody’s mood!
Mood Management Plans can be found in the toolkit.

**Formulation**

Imagine Bert, who seems to have become quieter over the past 2 weeks. He does not seem to put a lot of effort into the physiotherapy and OT sessions. When you tell him you have to re-arrange a session, he seems to deflate. He now spends most of his time lying on his bed. When his family visit, he smiles but he seems to be even flatter when they leave. What do you think is going on with Bert?

We have learnt earlier that a person who feels depressed tends to have a negative view of themselves, the future and the world around them. The depressed person will interpret things in a negative way. Bert seemed to deflate when you told him you needed to re-arrange the session. Typical depressive thought here might be:

You will notice that there is quite a range of thoughts Bert might be having, from not being liked to being a hopeless case. Rather than making an assumption, it is worth asking Bert, for example:

“You just looked really upset. Can you tell me what that was about?”

Bert tells you that he thinks that he will not get any better, and that he will be a burden to his wife and children. One way of making sense of what is going on is using a cognitive behavioural framework below. This shows how our thoughts, feelings, physical sensations and behaviours are linked. See the diagram below.
which shows how our thoughts, behaviour, emotions and bodily sensations can create a vicious circle of negativity.

You can find copies of blank formulation sheets in the toolkit.

Our approaches need to help people who have suffered a stroke to feel worthwhile and useful again. We want them to feel as though their future is worth working towards and we should provide some hope to them. Approaches will be offered (including psychological, social, medication) depending on the severity of the depression.

Let us have a look what this model looks like for Bert: his therapy session has been re-arranged, and he thinks this means he is not getting better. He is feeling down, his energy seems to drain away from him.

Like many people who are depressed, Bert withdraws into himself. He does not join in social activities, and he may decline therapy next time. As he feels more fatigued and also experiences more pain, his next session is less successful. This confirms his belief that he is not getting better. Because he also withdraws from his family, he is less fun to be around. His wife worries about him, but she also struggles with having to cheer him up. His concern that he is a burden to his family therefore may become true.
In the case of Bert, we can see that the physiological changes due to the depression confirm his belief. Most of our patients who are depressed do not realise that increase in pain sensation and fatigue can be due to the depression. Hence they assume things are getting worse rather than better, and they are understandably less likely to try. Remember, a person who is depressed has a negative view of the world, future and the self. The change in behaviour, for example withdrawing, tends to create the biggest problem, as this can lead to a self-fulfilling prophecy: the person stops trying in physiotherapy, and therefore actually stops progressing or even gets worse. Therefore, in order to break the cycle we tend to target the behaviour first.

**Intervention**

You will recall the tiered model discussed at the beginning of the mood section, and that most staff who are not mental health professionals would not be expected to treat the depression of a person with chronic major depression, or someone who displays depression with psychotic symptoms. However, as we mentioned earlier, all staff members should be able to recognise symptoms of depression and offer some form of support. For the more complex presentations (Tier 2 and 3) a mix of interventions from trained mental health staff plus medication may be offered.
Strategies for assisting with mood problems: Tier 1

This section refers to the interventions that all staff should be trained in to help an individual who is suffering from the effects of depression. Your assessment should give you ideas as to why the person is low (feeling worthless, a burden, being bored in hospital). Your Mood Management Plan will be based on the assessment, and might incorporate some suggestions described here. Core counselling skills as described in Part 1 of this manual will be needed at all times as people need to feel truly acknowledged with the belief that you are genuine in your quest to help them.

Activity Scheduling

Activity Scheduling is a simple behavioural intervention that is often used with patients who are depressed. Activity Schedules help people to re-engage in their lives and routines. We also use it to “test” some of the patient's negative assumptions (for example, “I don't enjoy anything these days”, “I can’t do anything anymore”).

When creating an Activity Schedule, the first step is to monitor the activity that the patient is currently engaging in. Establishing the current pattern and level of activity, we can ensure that any goals we set are realistic and achievable. When faced with their current activity levels, people are often either pleasantly surprised by how much they get done in a day, or shocked to see how much time they are spending doing little. Below is a small example of an Activity Schedule.

<table>
<thead>
<tr>
<th>Time</th>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
</tr>
</thead>
<tbody>
<tr>
<td>8-10</td>
<td>Lay in bed till 9, got ready, then made breakfast</td>
<td>Stayed in bed until 10</td>
<td>...</td>
<td></td>
</tr>
<tr>
<td>10-12</td>
<td>Sorted through some papers</td>
<td>Watched some TV, skipped breakfast, not hungry</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12-2pm</td>
<td>Physio came by, workout</td>
<td>Went back to bed, then got up for cup of tea...</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The diary shows us that the person was quite active on Monday, and did relatively little the next day. Once the person is comfortable with filling in the form, we introduce the second step: finding out how they feel during engaging in activities. By
asking them to rate their mood, we can find out which activities decrease feelings of depression, and which activities are exacerbating them. In the case below, the person is rating their level of depression: 100% = very depressed, 0% not depressed at all. Agree with the person which mood you are rating, and explain what the ratings mean!

<table>
<thead>
<tr>
<th>Time</th>
<th>Monday</th>
<th>Mood</th>
<th>Tuesday</th>
<th>Mood</th>
</tr>
</thead>
<tbody>
<tr>
<td>8-10</td>
<td>Lay in bed til 9, got ready, then made breakfast</td>
<td>30%</td>
<td>Stayed in bed until 10</td>
<td>80%</td>
</tr>
<tr>
<td>10-12</td>
<td>Sorted through some papers</td>
<td>25%</td>
<td>Watched some TV, skipped breakfast, not hungry</td>
<td>75%</td>
</tr>
<tr>
<td>12-2pm</td>
<td>Physio came by, workout</td>
<td>15%</td>
<td>Went back to bed, then got up for cup of tea...</td>
<td>80-85%</td>
</tr>
</tbody>
</table>

In the case above we can see that the person is rating their mood as more depressed when they are less active and spend more time in bed.

As a third step, you may consider adding additional rating scales. For example, you might ask the patient to rate on a scale of 0-10 their sense of achievement (A) while carrying out a particular activity, or their sense of enjoyment (E), with 0 = no achievement or enjoyment, and 10 = great enjoyment and achievement.

<table>
<thead>
<tr>
<th>Time</th>
<th>Monday</th>
<th>M, A, E</th>
<th>Tuesday</th>
<th>M, A, E</th>
</tr>
</thead>
<tbody>
<tr>
<td>8-10</td>
<td>Lay in bed til 9, got ready, then made breakfast</td>
<td>M 40% A 4 E 6</td>
<td>Stayed in bed until 10</td>
<td>M 80% A 1 E 3</td>
</tr>
<tr>
<td>10-12</td>
<td>Sorted through some papers</td>
<td>20% A 7 E 3</td>
<td>Watched some TV, skipped breakfast, not hungry</td>
<td>M 75% A 2 E 4</td>
</tr>
<tr>
<td>12-2pm</td>
<td>Physio came by, workout</td>
<td>15% A 8 E 8</td>
<td>Went back to bed, then got up for cup of tea...</td>
<td>M 85% A 1 E 3</td>
</tr>
</tbody>
</table>

What you may notice when looking at the form, is that our patient enjoyed staying in bed until 9 on Monday, but only got a moderate sense of achievement from it. The reverse was true when he sorted through some papers. Both enjoyment and achievement have an impact on his mood.
The aim of an Activity Schedule is to identify behaviours and activities that make an individual feel happy, and then to increase the frequency of these activities, thereby decreasing the amount of time that somebody is feeling depressed. By focussing on achievement, we might be able to help the person be more active even with tasks that they do not enjoy very much.

You can find blank Activity Schedules in the PAAST toolkit.

Problem Solving

Patients with anxiety and depression often feel that their problems cannot be solved because they are too difficult and overwhelming. This may lead to the person either trying to ignore and avoid their problems, or to resort to unhelpful ways to deal with their problem. The overall aim of problem solving with a patient is to increase their understanding of their own problems and set concrete and realistic plans to solve their problems.

We use problem solving where a problem is clearly identified. This involves generating different solutions to the problem, choosing the “best” solutions in collaboration with the patient, and supporting the patient to develop and carry out a plan. The plan is then evaluated to see if it solved the problem. This type of intervention can help a patient exert control over their lives, leading to improved mood.

This approach is similar to goal setting as it provides a way to encourage positive experiences, increasing the patient’s confidence and feelings of self-control. The process of problem solving with a patient can be outlined in seven steps.

Seven Steps

<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Clarify and define the problem</td>
<td>The problem should be concrete and specific</td>
</tr>
<tr>
<td>2.</td>
<td>Set a realistic Goal</td>
<td>SMART (Specific, Measurable, Achievable, Realistic and Timely)</td>
</tr>
<tr>
<td>3.</td>
<td>Generate multiple solutions</td>
<td>Brainstorming (5-10 solutions)</td>
</tr>
<tr>
<td>4.</td>
<td>Evaluate and compare</td>
<td>Weighing up the pro’s and con’s</td>
</tr>
</tbody>
</table>
solutions

| 5. Select a feasible solution | Least amount of effort, one with the least pro’s and con’s |
| 6. Implement the solution | Steps involved, support required? |
| 7. Evaluate the Outcome | Did it work/ not work/ why what would you do differently next time. |

You can find an example of a Problem Solving worksheet in toolkit in the PAAST toolkit.

**Motivational interviewing**

Motivational interviewing is a technique used by many health professionals to aid us when we are working with rehabilitation goals or promoting behaviour/ lifestyle changes. When working with an individual who is low in mood, you might find that they lack motivation to take part in therapy or work towards their goals. Motivational interviewing is all about getting people to want to change for themselves, rather than us simply telling them what they should or should not do.

Have you ever had an internal argument with yourself where it almost feels as though you have a miniature devil on one shoulder and a miniature angel on the other one? Perhaps one part of you is saying “eat a second slice of cake”, when the other part is saying “you’re supposed to be trying to eat healthily this week”. This kind of internal argument is often externalised by health professionals: we play the role of the miniature angel, telling people about all the positive changes they have to make and how they should go about doing it. This however means that the patient does not own these arguments, and is left with the role of the miniature devil – defending their choices and putting forward the other point of view.

Through motivational interviewing, we ask all of the right questions to get the patient to take control of both sides of the argument so that they are the ones coming up with reasons why they should change or why they should take part in an activity or goal. Someone is much more likely to run with an idea/plan of action if they came up with it themselves, than they are if you are just telling them what to do.
There is more information about motivational interviewing in the first part of this manual – including the different stages of change and strategies to use when you are met with “resistance” to change.

**Managing Depression: Tier 2**

NICE (2004) and RCP (2008) guidelines suggest the use of psychological therapies for mild to moderate difficulties. In particular, they recommend therapies such as Cognitive Behavioural Therapy (CBT) for post-stroke depression. Although trained staff may help to deliver psychological therapy, we can all help to understand a person, using basic CBT techniques. Take the example below:

George has a “script” in his mind which mirrors the symptoms of depression he is experiencing, he wakes up and tells himself “there’s no point in doing anything today as I’m useless and it will not make me feel any better”. That day he refused to do much. At the end of the day he felt dissatisfied, unfulfilled, and a little cross. His day had turned in to a no-win situation. He got no sense of pleasure or sense that he had mastered anything in his day, making him feel yet lower.

All staff can help George by listening to what he is saying, especially when he expresses his negative thoughts. This helps us to empathise with how he is feeling that day and the impact of his depressed mood on his thinking. Validating that when we are down we can feel bad and have negative thoughts may help and offering an option for George. You may suggest an experiment: “let’s see if we do something now whether it might make you feel even a bit better, or at least distract you”. Encouraging George to do something to see if this changes his mood, even to a small degree.

Giving an alternative opinion to his worst thoughts may also be useful: you may want to ask George when he suggests that he is useless if his family would see him that way or whether they have a different perspective on things. Feedback that the team working with him do not feel that way and respect him for his efforts and the progress he is making can also help.
Encouraging mastery and pleasure (this is the same as achievement and enjoyment mentioned in ‘Activity Scheduling’ above) every day and involving others to set goals with patients also helps greatly. Seeing important people in our life and getting out a bit where possible can help so much.

There are a number of resources in the toolkit that look at ways to help with depression, including an information sheet from the Stroke Association.

Managing Depression and pathways of care: Tier 3

The stepped care model of assisting people with more severe or complex depression advises that there are clear pathways for approaching specialist staff in mental health to assist in the assessment and treatment of the problem. Specialist staff will additionally consider past mental health issues, psychiatric history, personality functioning, substance abuse and a host of interconnecting issues such as family functioning etc.

A clear pathway for referral

If another professional working in mental health begins working with an individual, sharing your knowledge and understanding is invaluable, therefore offering your understanding of the known history about a person, and your observations can help put a picture together to help understand people’s problems, risks and likely needs.

Summary

The assessment and monitoring of mood is a crucial part of our care for stroke patients. This goes beyond administering a screening test once and noting the score. Our skills at being able to understand how it must feel to be the person with low mood is crucial to engagement. This allows us to appreciate the problems patients face. Through this understanding we can offer a framework to support the patient with mood problems, which will aid in their overall recovery. Monitoring and looking at measuring effectiveness of treatment approaches will be key throughout this process.
Anxiety

Anxiety is a normal human emotion that we all experience at times during our lives.

Imagine you are going to the dentist. You are sitting in the waiting room and you notice that slight pain in your tooth that made you make the appointment in the first place. People around you look uncomfortable, and then you hear the whirring of the drill coming from the treatment room. What do you experience?

Your heart might be beating quicker, your mouth may be dry, while your palms are feeling a bit sweaty. You also may be very alert to everything that is going on around you. You will probably worry that your dentist is going to use the drill, and that it is going to hurt. You might consider leaving, as the pain is not that bad after all…

What you are experiencing here is anxiety. Many people feel anxious, or nervous when faced with a problem at work, before taking a test, making an important decision or walking home from the bus in the dark. Anxiety is a normal bodily response to situations we consider dangerous.

Anxiety disorders

When our response to a certain situation is excessive or inappropriate, and interferes with our day to day life, we are talking about anxiety disorders. Let us consider an example: Floyd has an intense fear of sultanas. He does not like talking about them, looking at them and definitely will not eat them. He gets tense when ordering food in a restaurant, and worries whether the dish contains the offending ingredient. He worries he might get sick if he ate sultanas, and notices discomfort, nausea and a dry mouth. He usually manages his anxiety by avoiding bakeries, the baked goods aisle in the supermarket, restaurants, and Christmas puddings. Especially around Christmas this can be very difficult, as mince pies seem to be everywhere. To avoid this, he takes time off work and stays in the safety of his own home.

Even for those of us who do not like sultanas, we can generally cope with them. We might not eat them, but will not leave the room when someone else does. Floyd, however, responds with anxiety so severe that it affects his life and day-to-day functioning.

Anxiety disorders are actually quite common in the general population. Mixed anxiety and depression is the most common mental disorder in Britain, with almost 9% of
people meeting criteria for diagnosis (The Office for National Statistics Psychiatric Morbidity report, 2001). This means that nearly one in ten of our patients have some sort of anxiety problem before they had their stroke.

The diagram below gives you an idea of the different categories of anxiety disorders – it is based on the recent attempt to re-categorise the diagnosis for anxiety disorders, and is still under review (proposed DSM-V structure).

Anxiety disorders include fear of social situations (Social Phobia), fear of particular objects or animals (e.g. spider phobia), worry (Generalised Anxiety Disorder), fear of going outside (Agoraphobia) etc. Each anxiety disorder has its own diagnostic category and these are very different depending on the type of anxiety. Have a look at the diagnostic criteria for Panic Attack and Generalised Anxiety Disorder below:

**Table 1: DSM – IV TR Anxiety**

<table>
<thead>
<tr>
<th>DSM-IV TR criteria for Panic Attack</th>
<th>DSM-IV TR criteria for Generalised Anxiety Disorder</th>
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</thead>
<tbody>
<tr>
<td>A panic attack is a period of intense fear or discomfort, developing abruptly and peaking within 10 minutes, and requiring at least four of the following:</td>
<td>Excessive anxiety about a number of events or activities, occurring more days than not, for at least 6 months. The person finds it difficult to control the worry.</td>
</tr>
<tr>
<td>• Chest pain or discomfort</td>
<td>The anxiety and worry are associated with at least three of the following six symptoms (with at least some symptoms present for more days than not, for the past 6 months):</td>
</tr>
<tr>
<td>• Chills or hot flushes</td>
<td>• Restlessness or feeling keyed up or on edge</td>
</tr>
<tr>
<td>• Derealisation (feelings of unreality) or depersonalisation (being detached from oneself)</td>
<td>• Being easily fatigued</td>
</tr>
<tr>
<td>• Fear of losing control</td>
<td>• Difficulty concentrating or mind going blank</td>
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<tr>
<td>• Feeling dizzy, unsteady, lightheaded, or faint</td>
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<tr>
<td>• Feeling of choking</td>
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<tr>
<td>• Nausea or abdominal distress</td>
<td></td>
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<tr>
<td>• Palpitations or tachycardia</td>
<td></td>
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<tr>
<td>• Paresthesias</td>
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</tbody>
</table>
- Sensations of shortness of breath or smothering
- Sense of impending doom
- Sweating
- Trembling or shaking

- Irritability
- Muscle tension
- Sleep disturbance

Given how different these two anxiety disorders are, it makes sense that they have different treatments. You will not be required to deal with all of these disorders. However, it is useful to know that many of us find it uncomfortable to experience certain situations. When we declare someone as being anxious, this does not mean that they are anxious about everything, but possibly only about specific aspects in their life. Some of our patients might not like socialising in a larger group. Some may have certain ways of carrying out personal care tasks which seem excessive to us. A number of older adults have a fear of falling for instance. Understanding what someone is anxious about helps us to support them better.

Rates for anxiety following stroke have been estimated to be between 22-28% in the acute stage and at follow-up; that means one in four patients are anxious. It is important for us to identify patients with anxiety, as they are likely to suffer reduced concentration, attention and sleep, and this will impact on their rehabilitation. It has been suggested that those patients who experienced higher anxiety after stroke were more dependent with regard to their activities of daily living and had a reduced social network three years following their stroke. Anxiety also often occurs in conjunction with depression after stroke, and this tends to lead to poorer outcome.

**What is anxiety?**

While each anxiety disorder is distinctive, they are all marked by excessive and irrational fear, apprehension and difficulty managing tasks. Independent of the type of anxiety disorder, we tend to experience a set of biological, cognitive and behavioural responses.

**Biological response**

Anxiety is the response that our body produces in order to aid our survival when we feel threatened. This might happen when you are scared for your life, such as when we are crossing the road and a car comes towards us at high speed.
speed that we had not noticed. It can also happen when we feel threatened in a social situation, such as having to make a speech when we have not prepared for it.

Our brain assesses situations very quickly, and decides whether a situation is dangerous or not. If it flicks the switch indicating danger, it gives the signal to release hormones such as adrenalin into the bloodstream in order to maximise survival. This sets off the “fight or flight” response, preparing the body to either fight or to run away.

Adrenalin causes the heart to beat faster. This helps to increase blood flow in the areas where it is most needed. In the example of crossing the road, it means we can run faster, to get out of the way of the speeding car. Our breathing will increase to provide extra oxygen for the necessary energy. As out body works harder, we will feel warmer and start to sweat to cool us down. Our mouth becomes dry, and we may notice butterflies in our tummy as the digestion process slows down – the blood is being diverted to the areas where it is needed most, the muscles in arms and legs. We may also notice that our senses are becoming sharper, and we seem to be thinking more quickly.

This is an excellent response to help us in dangerous situations when we do not really have the time to think about what to do – it gets us ready for action quickly. In the case of the speeding car, this response will help us to move more quickly than usual and get us to safety.
Unfortunately, in order for this to work quickly, the response does not discriminate between different kinds of danger. For example, our body responds in the same way when our life is threatened, when we sit in the waiting room at the dentist’s or when we are in an uncomfortable social situation.

Most anxiety-provoking situations are relatively short-lived. Once the danger is over, our brain releases other hormones that help us to relax again. Generally, we are able to relax more quickly when there was a threat that meant we actually had to be physically active (e.g. run away).

**Cognitive symptoms of anxiety**

When a person is suffering from an anxiety disorder, they may experience psychological symptoms in addition to the biological symptoms described above:

<table>
<thead>
<tr>
<th>Psychological Symptoms</th>
<th>Behaviour</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mood</strong></td>
<td>Anxiety, irritability, feeling keyed up</td>
</tr>
<tr>
<td><strong>Thinking</strong></td>
<td>Worrying, thinking of self as vulnerable, difficulties concentrating, over-interpretation of threat</td>
</tr>
<tr>
<td><strong>Behaviour</strong></td>
<td>Avoidance, increased dependency, wish to escape</td>
</tr>
<tr>
<td><strong>Biological Symptoms</strong></td>
<td>Sweating, heart rate increase, palpitations, nausea, dry mouth</td>
</tr>
</tbody>
</table>

There is a diagram of physical symptoms of anxiety in the toolkit, along with a blank diagram that you may like to use with patients to find out how much they understand about their symptoms.

Those experiencing anxiety tend to consider themselves as **vulnerable**, and unable to cope. The future seems **unpredictable** and they view the world as **chaotic**. This tells us that the anxious person thinks of themselves of not being in control. Below is a diagram of the Anxiety Triad:
People will often react to the anxiety by *avoiding* stressful situations. For example, if you are afraid of the dentist, you may cancel your next dental appointment. You will notice that the apprehension you experienced will reduce pretty quickly.

**Case study: Kate**

Imagine Kate, who has come into the physiotherapy session. She is a little unsteady on her legs, and is notably nervous. After only 5 minutes of standing practice, she asks whether she can return to her room. She seems visibly relieved when you bring her back. Next time you come to take her to the session, she declines. You are worried that she is unable to make sufficient progress to return to independent living. What do you think is going on with Kate?

**Assessment**

It is important that we screen for anxiety, as it can severely interfere with the rehabilitation process, lead to worse outcome, higher dependence in terms of ADLs and reduced socialisation if left untreated.

As a first point of call, it is always good practice to just ask the person how they are feeling, and what is going on for them. That often gives us a bit of an idea of possible problems. If you see the person getting a little uncomfortable, just ask what is happening for them at the moment. You may also want to speak to family members to find out whether the person is usually anxious, what makes them tense, and what
helps them to feel calmer. Thinking of the example of Kate, we would ask her what happened in the physiotherapy session, and if anything made her uneasy. Kate tells you she noticed how wobbly she is, and that she is afraid of falling and fracturing her hip. Her family tell us she is usually quite a laid back person.

Of course, we also use questionnaires which help us to get an idea how severe the anxiety is:

The Hospital Anxiety and Depression Scale—Anxiety (HADS-A) is a screening measure for anxiety in those without significant cognitive or communication disability. It remains the only anxiety specific measure validated in stroke samples with published sensitivity (=0.80) and specificity (=0.42) data (i.e. it measures what it is supposed to measure). A cutoff of 6 or more was recommended for the seven questions of the HADS-A, used four months after stroke.

Depending on the severity of the symptoms, you may decide to refer the person on to a specialist in mental health such as a psychologist.

For those patients who are cognitively and/or communication compromised, there is to date no published validated measure or observer tool. In response to this,
Kneebone et al (2012) developed a 10-item rating scale to assist therapists to screen for anxiety: the Behavioural Outcomes of Anxiety (BOA). However, the tool is yet to be standardised, so there are no norms available. The researchers suggest that the BOA is a useful starting point to discuss the issue of anxiety with carers and family.

**Table 2: Behavioural Outcomes of Anxiety (BOA).**

<table>
<thead>
<tr>
<th></th>
<th>Often</th>
<th>Sometimes</th>
<th>Rarely</th>
<th>Never</th>
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<tbody>
<tr>
<td>1. Does he/she appear particularly tense or on edge?</td>
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<td>2. Does he/she have a strained face?</td>
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<tr>
<td>3. Does he/she avoid activities or social engagements without good reason?</td>
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<td>4. Does he/she appear fearful of falling?</td>
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<tr>
<td>5. Does he/she have trouble falling or staying asleep?</td>
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<td>6. Is he/she jumpy or easily startled?</td>
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<td>7. Is he/she restless or constantly on the move (e.g. do they pace)?</td>
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<td>8. Is he/she easily tired?</td>
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<tr>
<td>9. Does he/she appear anxious?</td>
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<tr>
<td>10. Does he/she appear to panic, or have unusual episodes of breathlessness or hyperventilation?</td>
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</tbody>
</table>

A tool like the BOA is usually completed with the primary carer. If there is an indication of significant anxiety, it is helpful to collect further information, e.g. through observation, in order to determine the cause of the anxiety.

You can find a copy of the BOA in the toolkit.

**Formulation: Anxiety**

We have discussed earlier that there is quite a range of different anxiety disorders, and it takes a certain level of knowledge and skill to recognise what you are dealing with, and to make sense of the mechanism. For example, you will not be asked to treat a person who has fears of contamination (obsessive compulsive disorder) or a specific phobia. However, there will be a number of patients we can all help.
We have learnt that a person who is anxious tends to feel vulnerable. Their fears are excessive and irrational, and they do not think they are able to cope with the situation. A good starting point when dealing with someone who is anxious is to ask them:

“You just looked really worried. Can you tell me what went through your mind?”

This is how we learnt about Kate’s fear of falling and breaking her hip. Thoughts like these will be picked up by the brain as a “danger” signal, leading to the release of adrenaline (we talked about this earlier – it is the biological response to anxiety). This means that Kate now also has to deal with a lot of unpleasant physical sensations that are the result of her feeling anxious. Again, we may want to ask her:

“When you just had that thought of breaking your hip, did you notice anything about your body?”

Have a look at the formulation of Kate’s problem on the following page. She did indeed notice a number of sensations, such as her heart racing, becoming sweaty, and her legs were starting to shake a little. While we know that this is a normal physiological response, that it is the effect of the adrenaline, Kate is now becoming worried about these symptoms. She believes they are a sign of her falling, her anxiety increases, and the symptoms get worse.
This is very common in anxiety. Many anxious patients notice the physical changes to their body and take this as proof that their fear is accurate. Thinking back to Floyd and his problems with sultanas, as he is feeling nauseous when seeing sultanas, he is taking this as confirmation that they are not good for him.

Like Floyd, Kate has found a way to end her anxiety: she is avoiding the situation. Many anxious patients do this, and the effect is pretty immediate. The anxiety reduces, and the person feels better. Unfortunately, it also means that the anxious person continues to hold on to their belief (this is the dashed line in the diagram): Kate is adamant that she will fall if trying to stand, Floyd is convinced that he cannot be in a room with a single sultana without feeling awful.
This means that avoidance is maintaining the anxiety. Some people may choose other behaviours to help them cope with their anxiety. They might rely on friends or family to come with them, or use a Zimmer frame when they could manage with a stick. The effect is the same as with avoiding a situation: the person does not find out that they can cope with the situation, and therefore the anxiety is maintained.

**Intervention**

So what do we do with someone who is anxious? It depends. If the anxiety is severe, we recommend you refer the patient to a mental health professional. We might offer relaxation, a form of talking therapy or medication that can help ease the anxiety. But there are things we can all do to help the person feel more in control of their situation.

**Common issues in stroke**

**Fear of the environment and ‘difficult situations’**.

Case example: A new patient comes on the ward and seems very restless. On speaking to the family, you find out they have always been a bit of a loner; they may not feel comfortable in social situations. They are probably finding it hard to be in a 4-bedder. For this person, we may consider placing them in a 2-bedder or even a single room. While not excluding them from social situations, we will give them the choice where to sit in the dining room, and if they want to join in smaller or larger group sessions.

We learn another patient gets agitated when they are alone. What would you do? We may offer them one of the beds in the bigger rooms, make sure they are not in the room at the end of the corridor, encourage them to join in the day room etc. There may also be items the person can bring along to the ward such as family photographs to make them feel more comfortable.

You can find a Worry Decision Tree, Worry Diary and Graded Hierarchy for Anxiety tool in the toolkit.
Toileting and Incontinence

Psychologists sometimes receive referrals for people having an ‘obsessional’ prooccupation with toileting – they buzz very frequently and ask to be taken to the toilet. A lot of the time, this will be due to the person worrying that they will wet or soil themselves. Whether this is due to mobility problems, the ward being busy or the carer not always being on time, this is a very understandable concern, as it can cause distress for the person and staff. How can we understand this issue? The formulation below can help us understand this fear better:

The diagram above shows the vicious cycle that anxiety can become. If somebody begins to get anxious about being incontinent, or not getting help to get to the toilet in time, it can become overwhelming to the point where they are pressing the buzzer for help very frequently (e.g. every 15 minutes). Perpetuating the problem further is the fact that frequent urination is in itself a bodily response to anxiety. It is therefore quite possible that they actually feel as though they need to urinate very regularly. A consequence to frequent buzzing may be that staff members begin to respond less quickly to this particular patient, as he is buzzing so frequently and does not always pass water.

By going to the toilet frequently, the anxiety is relieved for a short period of time, reducing the symptoms of anxiety that would otherwise be experienced. However, it
also may lead to the person being able to tolerate less pressure on their bladder and they need to go more frequently. Unfortunately, this can soon get out of hand and it is inconvenient for both staff and patients to go to the toilet so often.

So what can be done to help in this situation? All we might need to do here is to establish a regular toileting regime, letting the person know that they will be taken to the toilet at certain times of the day, and when that will be. In order for this to be effective, you need to fully explain the concept of the toileting schedule, and your reasons for putting it in place. Otherwise it can feel quite punishing. Find out if the person feels comfortable with the timing of toilet visits or if there is anything they would change about the schedule (within reason). By getting a patient on-board and involved with an intervention, they are much more likely to stick to it.

It is important when putting together the schedule that you gradually decrease the trips to the toilet, rather than making dramatic changes. So for example, if someone is requesting to go to the toilet on average 3 times per hour, do not change his or her routine to once every 3 hours. Instead, consider going once every hour, or once every 45 minutes, and gradually increasing the time between trips to the toilet.

It is crucially important that you are there with the patient when you say you will be. If the patient is not able to trust you or the schedule, it may cause more anxiety. You might ask the patient to ring the buzzer for help at the set times on the schedule (rather than relying on memory alone), reassuring them that someone will come as soon as they call for help.

If while using the schedule, an individual is consistently incontinent between trips to the toilet, you should consider reducing the time between toilet visits. Also, make sure that a patient’s usual toileting routine is taken into account. For example, if they always go to the toilet after a meal, or a cup of tea, try to build the schedule around these times in the day. It may be helpful to keep a diary of urination and bowel movements for 2-3 days before setting up the toileting schedule.

There are blank toilet schedules in the toolkit that can be used with patients.
Other interventions for dealing with general anxiety may also be beneficial, for example, teaching patients to use relaxation between toilet visits.

**Fear of falling**

This is a very common complaint following stroke. When we get older, our senses can become less effective at telling us how to move safely and without losing balance (proprioception). When you add to this the effects of a stroke with weakness to one side of your body and possible poor sense of balance (e.g. cerebellar stroke), it makes sense that they experience a fear of falling.

You need to know:
- What kind of stroke the person had, and whether it affects their balance
- Do they have visual problems – prior or since the stroke?
- Did they have problems with falls prior to their stroke? What helped?
- Did the initial fall happen when they were having a stroke?
- What are they afraid of? What do they think is going on?

Once you know the answer to all these questions, you will be better able to support the person. After a stroke, a fear of falling is not unreasonable or irrational as balance can often be affected. During intervention, explain to the person exactly what is happening, and check with them what can improve their sense of control. For example, in the case of Kate, you might ask her who she feels safest with. That person might support you in the physio session. Give exact information of what the intervention entails, and what will happen next. Negotiate how far you will take the session, and what Kate needs to say when she wants to stop.

There are few studies that identify management strategies for falls after stroke. Recent research suggested the use of yoga (Schmid et al, 2012) and adapted dancing (Hackney et al, 2012) in order to improve balance, and these claimed to improve balance – however, these studies are in their infancy, with small numbers of participants.
Health Anxiety

Some of our patients will present with excessive worry. Often this is related to having another stroke, or something dreadful happening to them. Think back to the anxiety triad introduced earlier. The person considers themselves vulnerable, the world as chaotic and the future as unpredictable. If the person displays significant worry, consider referring them to a mental health professional. A Cognitive Behavioural approach may be useful to address irrational and excessive worry.

The fear of having another stroke, unfortunately, is not unfounded. Therefore this is not irrational. Our responsibility is to provide the person with information about how to reduce risk factors, explain the medication they are receiving to them, and advise on healthy lifestyle. This might give a sense of control and empowerment. *(See the Unhelpful Health Related Thought Diary, Health Anxiety Thought Record and the Health Anxiety Pie Chart in the toolkit)*

Post Traumatic Stress

Unlike other illnesses, most people who suffer their first stroke will do so without having prior warning of something being wrong. Therefore, they could be coming from a position of being healthy and independent to one of being very dependent, possibly incontinent, and fearful for their life. Additionally, many patients do not remember the time they spent on the acute ward well or at all and this brings with it concerns about what actually happened to them.

It may be helpful to put together a scrap book for each person detailing their journey as they go through the pathway. This way we can build up a record of what has happened when they do not remember it. It will also be important to answer questions they have regarding the treatment they have received.

If the person suffers significant distress due to the trauma of their stroke or the hospital admission, please refer them to a mental health professional.
**Some simple anxiety management strategies after stroke**

Many patients are able to learn strategies to manage their anxiety- to use anxiety management techniques. Anxiety management techniques generally include:

- Understanding and identifying the symptoms of anxiety;
- Using breathing techniques or relaxation exercises to calm the body down;
- Using strategies to balance anxious thoughts;
- Facing situations/ building up confidence by breaking tasks down into simple steps and setting goals.

Below is an example of a breathing control exercise which can help.

**Learn Breathing Control**

This is a very simple way of learning how to breathe in a relaxed manner and also to restore normal breathing when you are anxious. It involves gentle breathing using the lower part of your chest, with the upper chest and shoulders relaxed. It is very important to breathe normally and not to hold your breath or take deep gasps.

- *settle yourself in a relaxed position*
- *make sure that your back is supported*
- *rest your hands on your lower rib cage/ stomach*
- *keep your shoulders and upper chest relaxed*
- *feel the gentle rising and falling under your hands as you breathe in and out*
- *find a rhythm that is comfortable for you. A general guide is to count in for four and out for four.*
- *concentrate on the lower part of your chest moving rather than the upper part*
- *do not try to take deep breaths*
The more you practise this the easier it becomes. You will then be able to practice it standing as well as sitting. Try practising regularly throughout the day and over time you will be able to use it whenever you are anxious. Some people find it easier to learn a relaxation or breathing technique with the help of a professional.

**Calming thoughts down**

There are a number of ways to calm anxious thoughts. These can be by answering the thought, or using self-talk (talking to ourselves in a compassionate way) that may help. Distraction techniques (eg trying to get our mind on to something else) can also distract our mind from the anxious thoughts.

**Summary**

Considering the impact anxiety can have on the person post stroke, it is important that we assess this appropriately and put in place a management plan. Unrecognised and untreated anxiety will lead to worse outcome for patients. This will be difficult for patients and can impair rehabilitation.

**References**


Anger

Anger is an emotion that we all feel at times. According to emotion theory (Darwin, 1872, Lazarus, 1991, Tomkins 1962), emotions are crucial vehicles for adaptation. They are a way of conveying information about the individual’s appraisal of their environment and helps focus attention on what is important to them. It can motivate and certainly help communicate. Anger can also cause harm to self and others. It can prevent an individual from thinking logically about their actions. It can place them at risk of impulsive behaviours. It can also get things done as when one is angry usually action has to occur from others. Anger then serves a purpose for us all.

Generally speaking, it is entirely natural to feel anger and in one sense it is important to convey how you feel – and sometimes after a stroke that might well be anger along with all the emotions mentioned throughout this section. We should not feel intimidated by anger, although it is recognised that when a person is in the throws of a very aggressive and angry outburst this is difficult and sometimes unsafe to stay with. We need to understand the anger as the persons core affect. It is likely anger is a result of a feeling of vulnerability or fear and rarely hatred or spite. We are likely to view anger as a threat and retreat. In some cases that is exactly what we should do if we are feeling threatened.

The trouble is we don’t like seeing people angry and we feel challenged by it so it is not the best form of communication generally but it is important for our patients to make use of their emotions to communicate their distress – and for some that is the only way they can (e.g. severe expressive aphasia, severe global cognitive impairment). Our job is to listen and understand that anger and help individuals understand their distress and release their emotions in a ‘safe’ and trusting relationship.

You will remember the section on core counselling skills. The capacity to fully experience one’s feelings, particularly when they are intense and/or painful, is greatly enhanced by being able to do this in a supportive, empathic and emotionally present relationship. Listening is of vital importance when our patients are expressing any emotion. This will create an environment where the patient is safe to ‘feel’ and given an opportunity to develop a way to process their emotions.
What causes anger?

Brain injury
An acquired brain injury can cause difficulties with recognising emotions such as anger as well as difficulties recognising ones behaviour and adjusting it accordingly. It might be that your patient is unaware that their behaviour is unacceptable and intimidating for others. It is possible that once your patient has become angry they find it extremely difficult to regulate their anger.

Personality type
Your patient might be described as an ‘angry’ person or have what we call a Type A personality prior to their stroke. This might increase the chance that having a stroke is likely to cause a degree of anger and hostility. You will need to find out more about this as there are likely to be some potential adjustment difficulties attached to this personality type that could create some challenges for all.

Life events
Major life events that cause loss, sadness, grief and pain happen to us all… Anger is not an unknown entity for many of those reading this manual. We have all probably
experienced anger in our lives. This might be at the end of a relationship as a major life event and it might last for some time and completely engulf your life as it usually mixed with other emotions such as grief, disappointment, envy etc. There is the short bouts of anger that we might have experienced, remember that person who cut in front of you whilst driving? Remember the bus driver driving straight past you at the bus stop when it’s the last bus home!!

Of course there are different levels of anger. The immediate physical impact is a heightened state of arousal – our blood pressure rises, we feel ready to act, we are breathing heavier and possibly our facial expressions change to fight mode (showing teeth, hands clasped). Some people experience “road rage” where they tend to experience an inappropriate level of anger while driving. There is anger that is quickly diminished, there is anger that lingers on the surface as we are steeped in ‘angry thoughts’ or feel wronged in some way.

**Thinking Styles**

How we perceive and understand events going on around us can affect how angry we feel about it. Have you ever had a friend who always jumps to negative conclusions about why somebody has done something? A classic example could be when a man buys his wife some flowers and she gets angry/annoyed/suspicious because she suspects he must have done something wrong! We all try to understand the intention behind people’s behaviour and sometimes we get this wrong, creating unnecessary or inappropriate anger.

How we think about anger itself can also affect how it is controlled or how it is expressed. For example, some people bottle up their anger and don’t talk about it, whereas others may feel that anger should never be bottled up and you should always express your feelings no matter what. Neither strategy is necessarily helpful, as someone who feels that they should always “unleash” their anger may never have had the opportunity to attempt to manage it in what could be a more appropriate way.

**Behavioural**

We all have different ideas of what is and isn’t acceptable behaviour. Some people will have learnt that expressions of anger get them what they need or want. It is
therefore a learned strategy that will be difficult to change with an acquired brain injury and with a traumatic event in the mix.

**Understanding Anger**

Anger, like anxiety and depression, is often the consequence of our thoughts rather than an actual situation. So for example, if a car pulls out in front of you, your interpretation of that situation may be that the driver mustn’t have seen you and that it’s an easy mistake to make, whereas someone else might assume that the driver did see them but pulled out anyway as they were too impatient to wait for you to pass. One of these interpretations would lead to feelings of anger, but the other one wouldn’t – even though the circumstances are exactly the same for both individuals.

**Anger and Stroke**

Anger is a normal reaction after stroke and something that many stroke survivors will experience. It could be anger at their situation, anger at themselves for doing something that may have increased their risk of stroke, anger at those around them (whether family and friends or staff members), anger over the things they have lost…. Anger can manifest itself in many different ways, from mild irritability to severe verbal/physical aggression towards self or others.

Some studies have suggested that quite a large percentage of individuals report significant aggression in the acute phase after stroke (17-35% - Aybek et al, 2005; Santos et al, 2006), and as we know, some individuals find it hard to control their emotions after stroke – this can include anger or aggression. One might also be more confused, bewildered, frightened or vulnerable in this stage and their only way of communicating that is through aggression.

You may find that some patients who go on to develop ongoing difficulties with anger and begin asking “why me” repeatedly. There is often a sense of injustice, particularly if someone has lived a healthy lifestyle and hasn’t done anything that would increase their risk of having a stroke but also anger at the dreams and hopes one might have had following their retirement, becoming a new parent/grandparent, getting that place at university or moving into a new retirement home that cannot cater for ongoing physical
dependence.

**Coping with Anger**

**Use coping strategies that have worked in the past**

The majority of our patients are older adults, and it is likely that by the age of 65+, most of them will have experienced many difficult situations which might have led to feelings of anger. Ask patients about the challenges they have faced in the past, and ask them what they did to cope then. You can then try and provide the means for them to use these coping strategies again – whether it is providing them with an outlet to do more exercise, ensuring they have someone to talk to and share their worries with, or making sure they are kept busy in order to distract them from dwelling on their anger.

**Ask patients to think about how helpful their current strategies are**

It is unlikely one will solve an ongoing emotion when their only expression of that feeling is anger. This is because we don’t like to be around angry people as we cannot rationalise them. This kind of behaviour can therefore begin to exclude and isolate the angry person. If a patient is refusing to engage in their rehabilitation programme because they are angry about having had a stroke this will impact on their recovery, prolong their stay in hospital and potentially limit their options on discharge. Helping patients to think about the long-term implications of maladaptive coping strategies might be beneficial.

**Relaxation**

Relaxation keeps getting mentioned throughout this manual and that is because it can be so effective for a wide range of different issues. Relaxation is something that you have to learn to do. It isn’t as easy as switching on a CD and listening to it – to truly relax, you need to leave your worries and stresses behind and be 100% in the moment. You are also less likely to click into relaxation mode when you are very angry. Your patient might respond well to relaxation if the ‘diagnosis’ of anger is correct and they feel heard and understood. Relaxation is about overall wellbeing and therefore proactive in managing ongoing issues with mood. Take the time to explain to them that relaxation doesn’t come naturally and that it may take time for them to feel fully relaxed.
**Problem solving**

When you have a problem and you aren’t sure how you can solve it, it is natural to feel quite frustrated and angry about it. For many people, it helps to break that problem down and look logically at the different steps that can be taken towards solving the problem. The overall aim of problem solving with a patient is to increase their understanding of their own problems and set concrete and realistic plans to solve them. There is more information on problem solving in the interventions section within this chapter, and you can find blank problem solving sheets in the toolkit, as well as an example showing how to fill the sheets in.

**Social support**

As with most things, talking about a problem or an issue can go a long way to making us feel better about it. If we are left to sit and stew and mull over a problem then it is likely that we will build it up in our heads to become something that is overwhelming and insurmountable. Talking to others about things that make us angry or frustrated can help to give us a sense of perspective as the individual listening, will often be in a better position to look at the situation as a whole and not just from our point of view.

**Distraction**

As mentioned above, mulling over a problem again and again can often make things seem a lot worse than they really are. It can quickly become all-consuming and all that we think about. One way to stop patients from doing this is to ensure that they have plenty of things to keep them busy. On a ward setting in particular, it is easy for an individual to become fixated on something as they will often be bored. Try to ensure there are plenty of things to break up an individual’s day and that they have activities to do that will keep their mind busy and active.

**Think positively**

Try to help patients to think and talk about all of the positive steps they have made. Sometimes all it takes is one bad therapy session to send someone into a spiral of low mood, frustration and anger. By ensuring that we always encourage them to focus on the positives,
and think about what they have achieved, we can go some way towards preventing this. Also, try to normalise their experiences, most people will have ups and downs after a stroke, and one very good session in physiotherapy, won’t necessarily be followed by another. Understanding that others experience the same problems can help to ease frustration and stop patients from blaming themselves.

**Challenging unhelpful thoughts**

We have talked quite a lot in this chapter, and throughout the manual, about unhelpful thoughts. Our thoughts influence our feelings and our behaviour and if someone is automatically having negative thoughts, and jumping to negative conclusions, they are likely to experience negative emotions such as anger. We can help people to challenge their unhelpful thoughts by first identifying these thoughts and then looking in more detail about how realistic these thoughts are.

So for example, if a patient is angry because they feel that staff members are purposefully giving them less therapy time than other patients, we can look at evidence for and against this assumption. We could look through the patient’s file with them, pointing out all of the therapeutic contact they have had, or ask other patients how often they have been having physiotherapy/speech and language therapy to compare. You could also teach the patient about unhelpful thinking patterns to see if they can identify any patterns within themselves. There are sheets in the toolbox which go into detail about the different types of unhelpful thoughts we experience, and these could be talked through with patients. There is also a “challenging unhelpful thoughts” sheet which can be used to pull together the pros and cons of thinking in a certain way.

Developing an understanding of the root cause of anger is important in order to establish good management techniques. Remember anger is normal; prolonged and unhelpful displays of anger are not normal and indeed in the long term potentially harmful.

**Conclusion: Mood and Adjustment**

Mood and adjustment problems following stroke are very common, and they frequently impinge on rehabilitation and long-term outcome. A substantial part of the needs of a patient with mood problems do not require specialist mental health professionals. We can all support the person by listening to them and their families,
asking what is going on for them and provide an empathic environment. We need to ensure that we assess for mood disorders, address any issues with a Mood Management Plan and continue to monitor the person in order to determine whether our plan is effective or needs to be adjusted, for example by referring to a specialist mental health team.