Part III - Cognitive changes after stroke

Part 3 – Cognitive Changes after Stroke
Cognitive changes after stroke

For the majority of staff members working in stroke, a basic knowledge of the different areas of the brain and their functions is extremely important. This allows us to gauge the likely impact a stroke will have on a person's functioning. However, because we are still learning about how the brain works, this can be a bit of a minefield as there are still conflicting opinions, and an awful lot to learn!

Learning Objective

This section will help to give you the knowledge and skills required to meet the following core competencies:

- Basic understanding of the neuroanatomy of the brain
- Basic understanding of the impact of damage to the different parts of the brain
- Basic understanding of the different types of stroke and the impact
- Basic understanding of assessment and treatment of a stroke

The brain

The brain is a very complex unit. Have a look at this diagram:

Like any other organ, the brain needs blood to function. Blood delivers oxygen to the brain and removes any waste material. A human brain accounts for 2% of a person's
body weight, but uses 15-20% of the body’s blood supply. Therefore, any disruption of the blood supply to the brain will have a major impact on its functioning.

Below is a diagram of the largest part of the brain, called the cerebrum. It has been split into four, easy to remember sections or lobes. As well as the cerebrum, there are two other main parts of the brain – the cerebellum which sits below the occipital and temporal lobe, and the brain stem which adjoins the brain to the spinal cord.

The cerebrum can be split into two halves – the right side and the left side, which are also known as hemispheres. We can distinguish between the right and left side of the four lobes. Apart from right and left, each lobe within the cerebrum can be split up further into much smaller sections that allow us to perform certain functions. However, for now we will just consider the main four lobes and take a look at what each lobe is responsible for.

**Frontal Lobe**

The largest lobes in the brain are the frontal lobes. They are often thought of as being home to our personality, as so many of the functions controlled here involve emotion, behaviour and decision making. Injury to this part of the brain can cause a huge range of symptoms and changes, and through studying people with brain injuries in this region, it has been discovered that the frontal lobes are involved in the following functions:
Parietal Lobe

The parietal lobe is located behind the frontal lobe at the top of the head and can again be split into the left and right hemispheres. Each side is involved in different functions, and produces different symptoms when damaged. As a whole, we know that the parietal lobe is responsible for the following functions:

<table>
<thead>
<tr>
<th>Function</th>
<th>Impairments following injury</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personality</td>
<td>Changes in personality and social behaviour</td>
</tr>
<tr>
<td>Motor function</td>
<td>Mood swings</td>
</tr>
<tr>
<td>Problem Solving</td>
<td>Loss of simple movement</td>
</tr>
<tr>
<td>Judgement</td>
<td>Sequencing - difficulties planning complex tasks</td>
</tr>
<tr>
<td>Spontaneity</td>
<td>Difficulties problem solving</td>
</tr>
<tr>
<td>Memory</td>
<td>Perseveration – repetition of actions</td>
</tr>
<tr>
<td>Language</td>
<td>Loss of spontaneity</td>
</tr>
<tr>
<td>Initiation</td>
<td>Loss of flexibility of thinking</td>
</tr>
<tr>
<td>Impulse control</td>
<td>Distractibility</td>
</tr>
<tr>
<td>Social behaviour</td>
<td>Reduction in attention</td>
</tr>
<tr>
<td>Sexual behaviour</td>
<td>Reduced concentration</td>
</tr>
<tr>
<td></td>
<td>Reduced abstract reasoning and imagination</td>
</tr>
<tr>
<td></td>
<td>Expressive language problems</td>
</tr>
</tbody>
</table>

As you can see, there is some overlap between the frontal and parietal lobes in terms of the functions that they perform and indeed this is the case for most areas of the brain. Although different lobes may contribute to the same function, the role they play will differ slightly. Using language as an example, the frontal lobe is responsible
for controlling the *muscles* that produce speech and sound (speech production), whereas the parietal lobe is thought to have receptive language functions (speech comprehension).

**Temporal Lobe**

The temporal lobe is located beneath the frontal and parietal lobes and plays a key role in memory and auditory functions (which makes sense as its right next to your ears!). This part of the brain is vulnerable to damage from stroke, and other acquired brain injuries. The key functions of the temporal lobes include:

<table>
<thead>
<tr>
<th>Function</th>
<th>Impairments following injury</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Auditory perception</em></td>
<td><em>Difficulty recognising faces</em></td>
</tr>
<tr>
<td><em>Processing of semantics</em> (meaning)</td>
<td><em>Difficulty understanding spoken words</em></td>
</tr>
<tr>
<td><em>Comprehension</em></td>
<td><em>Difficulty with selective attention to what we see and hear</em></td>
</tr>
<tr>
<td><em>Naming and categorising</em></td>
<td><em>Difficulty with identification of and verbalisation about objects</em></td>
</tr>
<tr>
<td><em>Verbal memory</em></td>
<td><em>Short-term memory loss</em></td>
</tr>
<tr>
<td><em>Memory acquisition</em></td>
<td><em>Interference with long-term memory</em></td>
</tr>
<tr>
<td><em>Spatial memory</em></td>
<td><em>Inability to categorise objects</em></td>
</tr>
<tr>
<td><em>Categorisation of objects</em></td>
<td><em>Right lobe damage may lead to persistent talking</em></td>
</tr>
<tr>
<td><em>Facial recognition</em></td>
<td><em>Increase in aggressive behaviour</em></td>
</tr>
<tr>
<td><em>Attention</em></td>
<td><em>Change in sexual interest</em></td>
</tr>
<tr>
<td><em>Personality</em></td>
<td></td>
</tr>
</tbody>
</table>

From looking at the list above, it is no wonder that damage to this particular lobe is thought to be responsible for anterograde amnesia (an inability to create new memories) as the temporal lobe plays such a crucial role in memory.

**Occipital Lobe**

The occipital lobe is located at the back of the skull, behind the parietal lobe and is the main area of the brain responsible for visual processing. The left and right occipital lobes are responsible for the following functions:

<table>
<thead>
<tr>
<th>Function</th>
<th>Impairments following injury</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Visuo-spatial processing</em></td>
<td><em>Visual field deficit</em></td>
</tr>
<tr>
<td><em>Colour recognition and discrimination</em></td>
<td><em>Difficulty recognising colours</em></td>
</tr>
<tr>
<td><em>Movement recognition</em></td>
<td><em>Hallucinations and visual illusions</em></td>
</tr>
<tr>
<td></td>
<td><em>Inability to recognise words</em></td>
</tr>
<tr>
<td></td>
<td><em>Difficulty perceiving movement</em></td>
</tr>
</tbody>
</table>
The list of functions may not be quite as extensive or diverse as those seen for other lobes; however the fact that the occipital lobe is so devoted to vision and visual processes shows how important these functions are to humans. Any damage to this area of the brain can lead to severe deficits in vision and recognition.

**Cerebellum**

The Cerebellum is located above the brain stem toward the back of the brain and is the second largest area of the brain after the Cerebrum. It plays a very important role in motor control as well as other functions such as:

<table>
<thead>
<tr>
<th>Function</th>
<th>Impairments following injury</th>
</tr>
</thead>
<tbody>
<tr>
<td>Motor Control</td>
<td>Loss of ability to coordinate fine movements</td>
</tr>
<tr>
<td>Coordination</td>
<td>Loss of co-ordination when walking</td>
</tr>
<tr>
<td>Balance</td>
<td>Inability to reach out and grab objects</td>
</tr>
<tr>
<td>Reflexes</td>
<td>Inability to make rapid movements</td>
</tr>
<tr>
<td>Timing</td>
<td>Movement tremors, dizziness</td>
</tr>
<tr>
<td>Attention</td>
<td>Wide based gait</td>
</tr>
<tr>
<td>Language</td>
<td>Slurred speech</td>
</tr>
<tr>
<td>Regulation of emotions such as fear</td>
<td>Abnormal eye movements</td>
</tr>
<tr>
<td>Pleasure responses</td>
<td></td>
</tr>
</tbody>
</table>

The role of the cerebellum is not yet completely understood in relation to emotion regulation and other cognitive functions. The majority of studies on this area of the brain have focused on movement and coordination, as this seems to be the most important role the cerebellum plays. It is thought that the cerebellum is not responsible for initiating movement, but rather for the fine tuning of movement, allowing us to move in a smooth, precise and well-timed manner.

**The Brain Stem**

The brain stem is somewhat different from other parts of the brain in that its functions and roles are all *critical* to life. The brain stem controls automatic functions, such as:
### Function

<table>
<thead>
<tr>
<th>consciousness</th>
<th>Impairments following injury</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breathing</td>
<td>Loss of consciousness</td>
</tr>
<tr>
<td>Heart Beat</td>
<td>Impairment of breathing</td>
</tr>
<tr>
<td>Alertness</td>
<td>Difficulty swallowing</td>
</tr>
<tr>
<td>Arousal</td>
<td>Double vision</td>
</tr>
<tr>
<td>Maintaining sleep cycle</td>
<td>Nausea and dizziness</td>
</tr>
<tr>
<td>Digestion</td>
<td>Loss of coordination, balance and movement</td>
</tr>
</tbody>
</table>

As obvious from the table above, this part of the brain is extremely important, because it controls the basic automatic functions that keep us alive. In addition, the connections from the motor and sensory systems in other parts of the brain pass through the brain stem to the body. The brain stem can therefore be thought of as a lone highway into a major city, without it, nothing can get in or out.

**Limbic System**

The limbic system is a group of brain structures that are involved in memory formation, processing and regulating emotions, responding to stress response to odours and sexual arousal. It includes structures such as the hypothalamus and thalamus, amygdala and hippocampus.

<table>
<thead>
<tr>
<th>Function</th>
<th>Impairments following injury</th>
</tr>
</thead>
<tbody>
<tr>
<td>Memory formation</td>
<td>Difficulties forming and retaining new memories</td>
</tr>
<tr>
<td>Processing emotions</td>
<td>Agitation</td>
</tr>
<tr>
<td>Regulating emotions</td>
<td>Difficulty controlling emotion</td>
</tr>
<tr>
<td>Stress response</td>
<td>Apathy</td>
</tr>
<tr>
<td>Response to odours</td>
<td>Olfactory impairments</td>
</tr>
<tr>
<td>Sexual arousal</td>
<td>Abnormal sexual behaviour</td>
</tr>
</tbody>
</table>

**Stroke**

If the supply of blood is restricted or stopped, brain cells begin to die. This can lead to brain damage and possibly death.

There are two main causes of strokes:

- **ischaemic** (accounting for over 80% of all cases): the blood supply is stopped due to a blood clot
- haemorrhagic: a weakened blood vessel supplying the brain bursts and causes brain damage

For a stroke to be diagnosed, the symptoms need to be present for 24 hours.

There is also a related condition known as a transient ischaemic attack (TIA), where the supply of blood to the brain is temporarily interrupted, causing a 'mini-stroke'. TIAS should be treated seriously as they are often a warning sign that a stroke is coming.

**Oxford Classifications of Stroke**

There have been various attempts to categorise and identify different subgroups (or types) of stroke, to help with treatment and prediction of likely outcome. The system most frequently used came from the Oxford Community Stroke Project and is often referred to as the Oxford Classification (or the Bamford Classification). It describes four types of stroke, categorised by the pattern of cognitive and neurological impairment that they result in. These include:

- Total Anterior Circulation (TAC)
- Partial Anterior Circulation (PAC)
- Lacunar (LAC)
- Posterior Circulation (POC)
Below is more information on the types of impairments which each classification of stroke can result in:

**Total Anterior Circulation (TAC)**

15% of all strokes meet this classification and there is a 60% mortality rate for individuals who have a TAC stroke. The symptoms observed following a TAC stroke include all of the following:

1. Higher cerebral dysfunction which was not present prior to the stroke. For example, dysphasia.
2. Homonymous Hemianopia (a loss of vision on the same side in both eyes).
3. Motor/sensory deficits on the same side of the body, occurring in at least two of the following: face, arm and leg.

**Partial Anterior Circulation (PAC)**

PAC strokes comprise of two of the three symptoms listed above for a TAC stroke. It may be that a patient presents with a higher cerebral dysfunction and less severe motor deficits, for example affecting just one limb.

Around 30% of all strokes meet this classification, and there is a mortality rate of around 16% for partial anterior circulation strokes.
**Lacunar (LAC)**

Lacunar strokes are characterised by small infarcts in the deep white matter or Basal Ganglia. Approximately 20% of strokes meet this classification, and the mortality rate is around 11%. Lacunar strokes comprise of purely motor or sensory symptoms – for example, dysarthria or ataxia. For diagnosis of a LAC stroke, signs and symptoms must include unilateral motor or sensory impairment of at least two of the following; face, arm and leg. In a LAC stroke, there would be no higher dysphasia or visuospatial impairment, and no signs of hemianopia.

**Posterior Circulation (POC)**

POC strokes comprise of one sided cranial nerve palsy plus one of the following; motor/sensory deficit occurring on both sides of the body, problems with eye movement, isolated cognitive dysfunction, isolated homonymous hemianopia, or contralateral motor/sensory deficit (affecting opposite side of body).

Twenty percent of strokes meet this classification, and there is thought to be a 19% mortality rate.

**Suffix**

You will often hear people saying that someone has a diagnosis of a TACI or a POCS. Another letter (S, I, or H) is added to the classification depending on the type of stroke that has been suffered (e.g. haemorrhagic or ischaemic).

- (S) – Syndrome – This diagnosis is made prior to imaging when it is not yet clear if the stroke is ischaemic or haemorrhagic (e.g. TACS).
- (I) – This diagnosis is given after imaging when *infarct* without haemorrhage is confirmed (e.g. TACI).
- (H) – A stroke which has been demonstrated through imaging to have been caused by a *haemorrhage* (e.g. TACH).

Haemorrhagic strokes are associated with having a very high mortality rate – thought to be around 50%. TACS will generally result in the most cognitive impairment (Barker-Collo *et al.*, 2012) and poorest functional outcome. LACI has the most positive functional outcome, although early functional recovery is a significant predictor of later functional outcome (Sprigg, N. *et al.*, 2007).
Although studies give us a general idea of the level of disability or impairment that will be experienced following stroke, case by case, this obviously depends on which area of the brain has been affected by the stroke, and how significant the damage is.
Cognitive difficulties after stroke

The word "cognitive" refers to the thought processes that are needed for awareness or knowledge. The following domains are included:

- Memory
- Attentional skills
- Abstract reasoning
- Visuospatial ability
- Orientation
- Verbal skills
- Cognition

It is without doubt that the focus of immediate rehabilitation after stroke tends to be on physical recovery. However, in a recent focus group patients stated that their mood and functions such as memory were not fully understood when they were inpatients (Brosnan, Watts, 2011). Cognitive impairments can result in confusion, distress, anxiety, low mood and carer breakdown if not understood and managed. Cognitive impairment can lead to functional impairment and difficulties with independent living on discharge. It can cause disruption of the ability to manage what is deemed an automatic activity.

Take for example, a simple task such as making a cup of tea. This actually places major demands on the cognitive system. The task requires the person to initiate, plan, organise, execute and complete the activity successfully. If cognitive function is compromised, you may also have difficulties with assessing risk (e.g. pouring boiling water over hands, taking a hot tray out of the oven without gloves) because your brain does not allow you to automatically review and adapt your behaviour based on that review.
The true nature of cognitive difficulties after stroke is not always known until the patient is fully aware of their environment and is communicating to some degree. We might hear relatives or loved ones begin to notice that the person does not seem as quick to process information or that they are not holding onto new information like they once did.

**Roles and Responsibilities**

Your patients rely on you to help them identify and work with all of their difficulties and strengths following stroke, they want to know what is ‘wrong’, and how they can get ‘better’.

Although you might have access to specialists in your team who assess cognitive difficulties and/or provide interventions/recommendations, your full understanding of cognitive difficulties following stroke is essential to inform your practice. Strategies for dealing with impairments do not only apply to formal rehab practice; they also apply to everyday tasks such as hoisting or enabling an individual to get to the toilet independently. By taking responsibility for cognition within your role, you will ultimately help to provide a better standard of care for the patients you work with.

Let us first think about the assessment process – i) when would we assess a patient, and ii) what do we need to consider?

**Assessment**

**When to Assess**

It is possible that your patient will be discharged without fully recognising his/her cognitive difficulties, or without being observed to have difficulty whilst on the ward. This is because sometimes it is only when a patient returns home or is in a work/education setting that the true impact on cognitive function is realised.
There are some key principles of clinical examination below:

- We need to objectively measure symptoms
- We need to check medical records and talk to families, friends, employers, college etc.
- Do not rely solely on what the patient tells you, as the patient may be in denial of their deficits or indeed unaware (anosognosic)
- Some patients may be exaggerating their deficits (e.g. malingering)

Here is a checklist you may find helpful:

**Is the patient reporting functional or cognitive problems?**

The kinds of reports one might hear is that they keep leaving taps or oven hobs on, or that they do not lock doors anymore. They might report increased frustration during cognitively demanding tasks, for instance sending an e-mail or talking to someone unfamiliar on the telephone.

**Are the family/relatives/carers reporting changes in personality, function or cognition?**

Family might report withdrawal or reluctance to engage in activities previously enjoyed. This may be due to cognitive problems such as planning and organising, but could also be down to low mood and/or fatigue.

**Assessment of cognitive function**

Where do I start? This question is reasonable to ask and there are no definitive answers at the time you first meet your patient, whether this is on the ward or in the community.

There are clear situations when a cognitive screen will be potentially harmful to the patient and actually not tell us very much. For example, a patient may be severely compromised due to advanced dementia, or if they are very early in recovery from a serious brain injury. In either of these cases we need to question the usefulness of the assessment and contrast it with the distress it may cause. Therefore screening does come with a caution
However, brief assessments can be very useful for tracking recovery and improvement, even in those patients who are in a minimally conscious state – the Wessex Head Injury Matrix (WHIM) for example, is one test that could be used in this situation.

Of course, there is no one test or screening tool that will tell you everything you need to know. All tools have their strengths and weaknesses and all tools should be used alongside observation. It is entirely possible that a screening tool does not indicate a problem, but a significant deficit is present that the tool has missed or not assessed.

**The Clinical Interview**

On first meeting our patient, we need to take a general history and cover the following points:

**General History**
- Patient and Informant
- Medications
- Previous significant health/traumatic injuries etc

**Establish a picture of pre-morbid functioning**
- Educational history, employment history, significant relationships
- The patient’s interests and hobbies

**Onset, time, course of the problems – were there problems prior to the stroke?**

**Self-reported difficulties**

**Note alertness and cooperation with the assessment**

**Note their appearance, how they interact on their way to the assessment, their eye contact, their concerns or what they might not be saying, their gait etc.**

Once you have gathered this information consider whether carrying out a screening assessment would be useful. If the answer is ‘yes’, then choose a test that has good
validity and reliability. Make sure you understand the test, know how to administer, score and interpret it. You will need to be able to tell others what the results mean (e.g. in the MDT, GP etc.).

The Cognitive Screen

There are many cognitive screening tools in use, varying in length, depth, time to administer, and their ability to pick out cognitive difficulties.

The following screening tools are included in the toolkit, along with instructions where appropriate.

- ACE-R
- MOCA
- Test Your Memory (TYM)
- 6-CIT

The following table lists which screening tools are validated for use with stroke patient, free to use, sensitive and specific, and can be completed in under 10 minutes:

<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>Addenbrooke's Cognitive Examination Revised (ACE-R)</td>
<td>✓</td>
<td>✓</td>
<td>✗</td>
<td>✗</td>
</tr>
<tr>
<td>Abbreviated Mental Test (AMT)</td>
<td>✓</td>
<td>✓</td>
<td>✗</td>
<td>✓</td>
</tr>
<tr>
<td>Cambridge Cognitive Examination (CAMCOG)</td>
<td>✓</td>
<td>✗</td>
<td>✓</td>
<td>✗</td>
</tr>
<tr>
<td>Middlesex Elderly Assessment of Mental State</td>
<td>✓</td>
<td>✗</td>
<td>✗</td>
<td>✓</td>
</tr>
</tbody>
</table>
The following section deals with common difficulties observed in patients who have problems with their cognition. In particular we will be discussing insight and awareness, attention and concentration, orientation, executive function and memory.

**Insight and Awareness**

Imagine the case of Ralph, who is in a wheelchair following a right TACS and is not able to walk. He appears ok in his mood, and is looking forward to an overnight stay at home. He has refused a commode, as he wants to use his upstairs bathroom. When asked how he will manage to get up the stairs, he tells you he will just walk. Ralph is not being awkward, he has reduced insight.

Decreased self-awareness and insight can have a big impact on neuro-rehabilitation. If you are not aware of your disability, this can result in risky behaviours – the man in this picture when faced with stairs, may attempt to get out of his chair and walk up the stairs without reflecting on advice given by the physiotherapist that he must not. He may not be able to retain this information or does not believe it!

Apart from engaging in risky behaviour, patients might also decline physiotherapy, as they do not think there is a problem. Therefore, they are at risk of making a poorer recovery than predicted.
There are many reasons why a patient may lack insight into their difficulties, some of which are listed below:

**Anosognosia**

The patient is unaware of their disability. It differs from denial in that the person genuinely does not know the extent of their disability or impairments. Anosognosia tends to be caused by damage to the frontal or parietal lobe.

**Impaired self-monitoring**

An individual may not be aware or able to observe their mistakes or errors. They may say something completely inappropriate in conversation but be unaware that they have done so.

**Impaired Reasoning/Thinking Skills**

An individual might be aware of mistakes they make, or of a particular impairment they have, but lack the ability to make a connection between that impairment and the potential consequences. So for example, someone may be at risk of falling due to weakness in their left leg. They might be fully aware of this weakness and the difficulties they have with walking but still not understand why they are at a risk of falling.

**Impaired Attention and Concentration**

A person may not have the ability to attend to conversations, or hold their concentration for long enough to take in what others are saying to them. Therefore they may not be able to take in information about their difficulties or receive feedback about their performance or ability to do certain things.

**Impaired Memory or Learning**

If an individual has difficulties retaining or retrieving information, they will find it difficult to remember information provided by staff in relation to their overall care. They may quickly forget the advice they have been given, forget errors they have made previously and how they have been advised to avoid these in the future.
**Emotional Coping or Acceptance**

Following a stroke, an individual has to deal with the changes that have occurred to their body, mind, behaviour or personality. While some patients do not seem to have insight into their difficulties as described above (they really do not know), others seem to be in denial. This means they cannot deal with the reality of their situation at present, and insist that their problems are not as big or that they will be fine. They might try to prove they are not impaired, for example attempting to stand up and walk when they have significant physical difficulties.

**How can you help?**

Many survivors of stroke experience a reduced capacity for insight, self-monitoring, and awareness. They may have difficulty understanding the relationship between their behaviour and consequences and may experience confusion or frustration in their attempt to understand situations. The strategies you can use with patients will differ depending on your assessment or understanding of the problem. If the problem relates to difficulties retaining information, then strategies should support the memory. If the problem is due to reasoning or thinking skills, it can be helpful to use strategies based on planning or decision making.

**Assessment**

Firstly we need to assess the person's awareness, which will be tested through questioning and screening. Some patients learn to repeat what they have been told (“I am in hospital, I have had a stroke”), but continue to be disorientated as they lack awareness. Level of awareness can be assessed using the Awareness Questionnaire (in toolkit). Your patient’s level of awareness can be viewed like this:
As you can see from the model, there is a difference between ‘knowing’ that you have a disability, knowing what effect the disability has on you, and knowing what you can do about it in order to compensate. Once we know what level of awareness the patient has, we can support them appropriately.

**Provide Feedback**

Non-critical, constructive feedback is essential in helping people understand their strengths and relative weaknesses. Feedback should be concrete (plain and clear) and specific, for example; “I noticed that when you were lifting the weight with your right arm, you weren’t able to lift it as high as you could with your left arm without feeling pain...”. If an individual has memory problems, then writing this down in a ‘working document’ which they can look at and which can be constantly referred to will help to consolidate that information. It might also be helpful for relatives/carers to read this, to support repetition of accurate information.

Do not dwell on negatives for too long, especially if the person seems distressed by what they are hearing. Try to give constructive advice for how they can improve and provide an avenue for goal setting. Tell the person what they are good at too.

**Provide Information**

Having had a stroke and not being sure about what this means can be very upsetting. For many patients receiving information about what has happened is not
only reassuring, but might help them to feel less isolated and provide some realistic hope. Some patients will be able to seek out the information themselves; more and more older adults are using the internet for example (although this can also provide quite frightening information). After stroke, they may no longer be able to search for information independently; due to their environment or physical/cognitive difficulties, and we can support them in this.

**Family and Friends**

Family and friends can offer vital support not only to patients but also staff! Often patients are more likely to listen and take notice of what their loved ones tell them than you! As they have known the person before their stroke, they may be able to recognise changes and highlight these in a supportive and timely manner for your patient. It can be a good idea to get relatives involved with rehab, perhaps attending a session with the therapist on occasion.

**Encourage**

Simply talking *at* an individual will usually result in a poorer understanding than you would get if you talked *with* an individual. Encourage the patient to evaluate their own performance, that way you can get a grasp of how far removed your patient might be from the reality of the situation. Ask them what they thought went well and what they might do different next time. If they are struggling to come up with ideas, use prompts to help them but make sure they have some input (e.g. focus on the most recent session and give clear and honest information about that session to help focus your patient on situational (and therefore in context) examples.

**Here and Now**

When a patient persistently lacks insight and seems oblivious to their deficit (e.g. walking), it can be helpful to gently re-orient them to the present. For example: “How did you get to the dining room today? … What did you do in your last physiotherapy session?” You are not saying to them that they will never walk again, but asking them to reflect that they are not walking at the moment.
Attention and Concentration

Attention is a function which we do not often think about as we are going about our day to day lives. We can sit in a room filled with objects, sounds and other people and can focus fully on the computer screen in front of us. It is attention that allows us to do this. Attention is our ability to select one piece of information or one stimulus from the various possibilities provided to us by our senses, and focus on it alone.

To do this, we have to depend on our ability to ignore other information and filter it out into the “background”. In a crowded bar with music playing and lots of people talking to each other, we maintain the ability to hold a conversation as we filter out all of the irrelevant information coming in to our senses, and focus only on our conversation.

Impaired attention and concentration are among the most common cognitive problems associated with acquired brain damage. The patient may be capable of better than average performance on tests of memory, intelligence, problem solving etc., yet overall their cognitive productivity suffers from inattentiveness, faulty concentration and/or fatigue.

Attention has several different aspects. Imagine going into the kitchen to make a cup of tea and some fried eggs on toast. You need to be able to focus on the items you need. When frying your eggs, you need to keep an eye on it so they do not get burnt. You also want to make sure that you use the water when it has boiled, and that the toast is not already cold by the time the eggs are ready. All of this requires different aspects of attention.
**Focused or selective attention**

This is the capacity to focus on the one or two important stimuli or ideas currently being dealt with while ignoring competing distractions. It is commonly referred to as concentration. Making that cup of tea will require focused attention for instance.

**Sustained attention or vigilance**

This refers to the capacity to maintain an activity over a period of time. Completing a jigsaw puzzle or studying for an exam is a good example.

**Divided attention**

This involves the ability to respond to more than one task at a time or to multiple elements or operations within a task, as in a complex mental task. It is thus very sensitive to any condition that reduces attentional capacity. For example, think of a taxi driver who is talking to his passenger whilst working out the route he is going to take and listening to the message from the central office. If you had difficulty with divided attention you would struggle to carry out many tasks.

**Alternating attention**

This allows for shifts in focus and tasks. This often happens in our work when we are typing a report we are focused on that report then the telephone rings and suddenly you have to concentrate on requests on the other end of the phone. The strength is that your brain is then able to go back to the report once your phone call is dealt with.

Your patient is likely to complain of one or more of the following when they have difficulty with attention/concentration:

- I can't keep my mind on what I'm doing.
- I forget what I came into a room for.
- I can't concentrate if it's noisy.
- I have to ask people to repeat things.
- I can't do more than one thing at a time.
- I lose track of what I'm trying to say when another person walks in the room.
- I can't do mental arithmetic anymore.
How can you help?

Environmental Supports

By adapting the environment, we can make everyday tasks much simpler for those with attention difficulties. Used later in the recovery phase, environmental supports should be considered to help assist reintegration in the home, community and work place. Adapting the environment can be more difficult in a hospital setting where there are many distractions such as noise and background conversations. There are some simple adaptations that can be made to the ward environment, for example:

Attention problems can be aided by taking noise or distracters out of the environment (or taking patients out of a noisy environment!). If you are visiting a patient in their home, try to find a quiet room with no distractions such as a television or radio. Ask your patient whether there are any distractions in the room to help raise their awareness of the impact the TV or radio could have on their engagement. If you are working on the ward with a patient, if possible go to a quiet room. Alternatively make sure the curtains are drawn so there are no visual distractions.

Ensure that patients only need to focus on one activity at a time. If an individual is having problems with divided attention, make sure they are clear on what it is they need to do before they start. Chunk the procedure of the task to allow them to become confident with each level. Giving instructions while they carry out the task is likely to be a distractor, for example, walking after stroke sometimes requires a great deal of attention, therefore do not attempt to engage the patient in conversation or say ‘hello’ as this is likely to distract them.

Allocate sufficient time to complete tasks. Knowing there is pressure to get something done quickly can be enough of a distraction in itself to hinder patients' success with the task.
Talking to your patient

By adjusting the way we interact with our patients, we can maximise their attention. Talk to patients in concrete and easy to follow language. Patients with limited attention are likely to struggle to keep track of long verbal or written explanations, especially if it is new and out of context. Remember that for the majority of patients, any conversation about stroke or rehabilitation will be new. Even if some have knowledge about stroke, this may be inaccurate.

Use ‘chunking’ to help patients keep track in conversation and to aid understanding. Chunking is providing small pieces of information – for example a shopping list may be divided into 3 chunks or “mini lists” for fruit, meat and dairy. If you say too much you will lose your patient’s interest and attention, potentially wasting valuable time and more worryingly disempower your patient. Culturally we do not tend to feel comfortable with silences but actually this can be very helpful for your patient. It can allow some time to process or think about what has been said. A short silence can ensure your patient has understood what you have said and will also give them the chance to ask questions.

External Devices

External devices can be adopted to support patient’s difficulties with tracking time, organising and responding to external stimuli, and one-to-one interaction. Below are some external devices you could use with patients:

Written calendars/day planners/timetables

A calendar or timetable should be placed in an area your patient has full access and should always be very visible. Take into account possible visual difficulties he or she may have. Staff, family and friends should use this system and refer to it at every opportunity.

A blank timetable can be found in the toolkit.
Written checklists

These need to be succinct and concrete so that the individual does not need to attend to them for long periods of time. Think about the helpful instructions you can get with DIY furniture and how well written instructions compare with poor quality instructions. Here’s an example when making a cup of tea:

1. Get cup out of cupboard
2. Place cup next to kettle
3. Push on button on kettle
4. etc etc

An example checklist can be found in the toolkit.

Electronic organisers

These can be a little expensive depending on what you select, but if your client has a mobile phone, smart phone or i-pad for instance, this could be very beneficial to their rehabilitation and independence. They can be particularly helpful for those patients who are already used to using this kind of technology.

Voice message recorders

Some electronic devices allow you to leave voice messages with patients. The message could give instructions to an individual to help them pay full attention and avoid losing concentration by carrying out one task at a time, for instance, a cooking or dressing task. The voice message could go through different instructions individually and could remind the person to go back and check on something on the hob for instance after a set amount of time.

Internal Management

As well as making changes to the environment or giving individuals external devices to help them maintain attention and concentration, you can also help them to develop a ‘mantra’ to help them take the steps needed to make a cup of tea for example. Another example could include a patient walking with a frame and repeating to themselves (either out loud or in their head), “left foot, right foot, frame”. This will help them to stay on task and prevent becoming distracted by the environment such as people walking past or people talking in the background.
**Attention Process Training (APT)**

Attention Process Training is a tool developed for mild to severe attention difficulties and for use with the adolescent and adult population. This is a costly intervention and one that needs to be carried out by a trained professional. We have listed this here for completeness - however, should you be interested in finding out more there is a great deal of literature on the subject of Attention Process Training for acquired brain injury.

**Psychosocial Support**

This will involve finding out more about your patient and the underlying difficulties they are experiencing. How much does your patient understand of their stroke? Are they living in fear of having another one? Do they know their risk factors and how to reduce them over time?

The psychological impact of stroke and the traumatic experience of it should not be forgotten as this can severely impact on levels of stress and anxiety and consequently cognitive function.

By offering psychosocial support to patients, you will be able to explore their reactions to their stroke but also how they are adjusting. Reactive effects can include grief, anger, denial, depression and anxiety. These are basic emotions caused by an experience or event; in this case it is the experience of stroke. All of these emotions can affect an individual’s capacity to process information, and can pose a barrier to rehabilitation.

Psychosocial approaches should be used in conjunction with cognitive rehabilitation in order to address both organic brain damage and psycho-emotional effects of brain injury, including brain injury from stroke. This can be achieved through patient-centred practice and the patient-therapist relationship. By involving the patient, this can improve their feelings of control over their situation and potentially decrease feelings of loss and distress.
Orientation

Orientation refers to a function of the mind which allows us to be aware of time, place and person. Even when not wearing a watch, we tend to have a rough idea of the time and date. The majority of us know which month and which year we are in. Following stroke however, individuals can become disorientated in time, place or person, or a combination of these three dimensions. Generally, disorientation is most common with regard to time, then to place, and finally to person.

We take for granted that we know our environment and can find our way around using our visual memory and visual cues. Imagine Florence who has come to the ward two days ago. She does not know where she is, and does not recognise her family when they visit. In the case of Florence, it seems obvious that she is not orientated. However, we should always assess orientation to ensure that we do not miss subtle disorientation. A simple assessment of orientation can be achieved by asking the following questions (which can also be found in the toolkit):

**Time**

- What time of the day is it?
- What year are we in?
- How long have you spent in hospital (temporal orientation)
- How long is it until lunch?
- When did you last eat?

**Place**

- Where are you right now?
- Where do you live?
• What city or town are we in?

• What is the nearest landmark to where you are now?

**Person**

• What is your name?

• What is your date of birth and how old are you?

• Do you have any children?

• Are you married?

• Why are you here?

There are many reasons why someone with a brain injury such as stroke might become disorientated:

• Their brain injury may prevent them from laying down new memories. The patient could be in PTA (Post Traumatic Amnesia) or have varying levels of consciousness and may therefore be unable to make sense of their environment.

• The patient’s attention and concentration may limit their ability to take in new information and or recall accurate information.

• The patient’s autobiographical store might have been damaged by their stroke.

• The patient could have anosognosia and may therefore be unable to recognise their illness.

• The patient might have landmark agnosia and cannot make sense of their environment.

• The patient may be unable to recognise faces (prosopagnosia) and therefore unable to recognise individuals. This is a rare presentation, and likely to be noticeable early on. This condition is often very distressing to patients.

Imagine not knowing where you are and why. Not knowing your age or the age of
your children when questioned. This can have a significant impact on confidence, anxiety and self-esteem and be a source of embarrassment for some individuals. Dependent on what other difficulties your patient is experiencing there are simple methods of helping orientate your client.

**Case study:**
Mavis is 84 years old lady who has recently suffered a TACS and was admitted to the ward. She appears to understand what you say to her but she has limited communication (difficulty expressing one word responses but can write responses on a notepad). She is looking around the ward and appears at times to be frightened (her eyes open wide). At other times she is withdrawn, responding only to interaction from her family. She is able to communicate to you ‘why?’ holding her hands up.

She might be asking this question because she is frightened and does not know what has happened to her. You should think through the following questions:

1. Is she aware that she has had a stroke?
2. Is she aware she is in hospital?
3. Is she aware of who you are as staff members?

Try to think of some ways you could find out this information from Mavis. How can you support her to express her feelings about the situation?

The method used to help orientate an individual to their immediate environment is dependent on several factors: i) the capacity to understand written and auditory communication, ii) attention/concentration, iii) memory, iv) mood, v) location and extent of brain injury, vi) fatigue vii) awareness of their environment, viii) other cognitive/sensory difficulties

**TASK:**
Think for a minute about what you need to orientate yourself to different environments. For instance, when you are on holiday abroad in an unfamiliar place and you wake up in a room and for a few seconds your brain does not quite know where it is – what helps?
Familiarity is key to orientation. It can be frightening to not be fully aware of your environment. Therefore we tend to take things with us that help with orientation, such as a watch, phone, or bag containing familiar things.

**Case study:**
Nafeesa arrives on the ward having had a stroke. She wakes up in a bed on a ward and is looking around frantically for something to help her to understand where she is. She calls for her husband who is always in the bed next to her. She is not used to being on her own and is terrified.

This lady is disorientated. It might be fleeting and she might be able to retain information about where she is and what happened to her. To help her understand and make sense of the environment we need to provide her with information in language she will understand. Check that she understood, for example by asking the questions outlined above (awareness of stroke, being in hospital, and regarding staff). Give her time to work it out from her environment by encouraging her to look around the room and perhaps focus on something that belongs to her such as her dressing gown.

**How can you help?**
This depends on the individual. How did the individual communicate before their stroke? Did they speak English, could they read and write, did they have visual impairment, or were they hearing impaired? Did they have other pre-existing problems like dementia, and if so, how advanced was this? Additionally, what impairment are they likely to have following their stroke? Have they already displayed deficits?

Armed with this information, we can build up a picture of the patient, a holistic formulation (in the toolkit), and can help the person in the most appropriate way. Two main areas in which we can support the person are through external support and adaptation of the environment.
External Support

Scripts
In psychology, we think of scripts as organised patterns of thought and behaviour, a framework that represents aspects of our world. In the current context, a script provides information to help the patient to be oriented towards time, place and person etc. Depending on your patient’s needs, orientating them to a script can work very well (see the toolkit for an example of a Script). Establish first of all what your patient needs to know and wants to know. Take this very simple example, Robert has just been admitted to the rehabilitation ward from the acute ward and is puzzled and distressed by his surroundings. He has asked staff a few times where he is and what has happened to him. To ease his distress, we may address the following areas:

Goals:

- Robert will know where he is, e.g. *Where am I?* You are in the Stroke Rehabilitation Ward, General Hospital.
- Robert will have a basic understanding that he had a stroke and what this means, e.g. *Why am I here?* You are here because you had a stroke. This is why you cannot use your left arm.
- Robert will have a general idea how long he will be on the ward, e.g. weeks rather than days. E.g. *When can I go home?* You will be here for another two or three weeks; this means the end of September

We might not know the discharge destination at this point. Early on, we may decide not to discuss the possibility of nursing home care with a patient, if we feel this could cause undue distress. However, this would have to be reviewed in due course.

The script should be put together with your patient, so you can ensure that they understand the language, read the typeface and that they can see the information clearly. A schedule of reinforcement should also take place so that your patient is hearing this information regularly.
Clocks and Calendars

Have you ever been off work for a long period of time? The days do tend to blur into one without any structure, and this is exactly what can happen when you have been in hospital for a while. For many of us, our everyday routines tell us what time it is, and booking things into our diary or looking at our mobile phones will help us to know where in a certain month we are.

It sounds obvious: providing a clock within sight, and a calendar is a good idea for all patients, and especially for those having problems with orientation.

A simple calendar printed off the computer is often sufficient and can also be used as a diary for making a note of appointments, visiting hours and rehab time in the gym etc. Talking clocks and calendars are also beneficial for those with visual impairment.

Whiteboard

Most patients will have a whiteboard above their bed when they are on the ward and you should use this not only to make notes for staff to read, but also to help orientate the patient. Often we ask patients what ward they are on, or what floor they are on, but these questions can be tricky if there are no obvious signs to inform patients exactly where they are. Make a note of their location on the whiteboard – “Mrs X, Ward 5, 2nd Floor, X hospital”. You can also use the whiteboard to note the date, and the day’s activities for the patient, for example “Wednesday, 3rd May 2013, 10:00a.m. – Physiotherapy, 12:00p.m. – Lunch Time, 2:30p.m. – Daughter Visiting…”. This will give the day a bit of structure and help orientate the patient to the time of day.

Your role

External support also includes staff. Always introduce yourself and your role to your patient, even if they appear to recognise you. Of course you can stop doing this when they start rolling their eyes at you and shouting “I KNOW!” but individuals who have awareness or orientation difficulties are not always going to admit that they don’t recognise you. It could be that their automatic and appropriate
response to you is friendly and welcoming and this could fool you into thinking they recognised you when they have not.

If you are going somewhere with your patient, for example to the gym, tell them where they are going and what they will be doing. When they are finished, make sure you re-orientate them to their environment and encourage them to direct you wherever possible to their bedside or room (rather than you leading the way). Encourage independence in their environment by helping them to take responsibility, for instance, when in a wheelchair ask the patient – which way do we go now? Or get them to point in the direction of the place they are trying to reach.

Encourage patients to pay attention to their environment by pointing out colours of the walls and landmarks on the route, such as photographs or paintings on the wall. Take the same route each time so that they can have some familiarity with you and the place you see them, allowing them to gain greater control of their environment even if this is for one individual therapy.

Goal Setting

We have mentioned goal setting before. This is essential for the patient to understand the aims and expectations from them. They can monitor their progress and begin to learn what their difficulties are and how to manage them. There are goal attainment scales (GAS) in the toolkit, which you can use with patients (see the toolkit).

Orientation Groups or 1:1 work

It can be helpful to offer some group activities which will help patients to gain an understanding of the time/date or their environment. These do not have to be overly complex and will not take a lot of time to plan. The following ideas can be used either in groups or 1:1 with a patient:

- Reading the newspaper referring to the day and date
- Reading sections of the newspaper with current events and having a discussion about this
- Orientation quizzes
• Discovery trails to find out about local environment; this can be done with regard to the hospital, nursing home, residential home or to the patient’s family home.

The Patient’s Environment

Familiarity
Dependent again on your patient’s presentation and assessed difficulty, having familiar objects around them could help create a calm environment to which they can relate. The use of photographs and familiar objects or smells can help relax patients and also help with memory. If you are working with a patient who is not attending to their right side, you could try putting up a display of photographs to their right, encouraging them to look towards it.

If you have a patient who feels that it is important to them to wear their make-up every day, make sure they have the tools to do so. This could be an important part of their identity. Anything which helps patients feel more like themselves should be encouraged as much as possible.

Visual landmark orientation
Ensure the environment is organised and has appropriate labels to help clients to orientate themselves. If all doors look the same down a long corridor, it is unlikely that a disorientated patient will find their way to their room independently. However, your patient may be able to learn an association to their room. This could be a different coloured blanket on the bed, a sticker on the door with a particular colour or shape on it, the patient’s name or even a picture. This will help alleviate the anxiety that being disorientated can cause.

Labelling rooms such as the bathroom, toilet, kitchen and dining room could also aid reorientation to the environment. Whilst you are directing the patient to these areas, work towards more independence by pointing out the room you are going to and telling them where they are. Help them to think about how they will get back to their bedside/ house dependent on where therapy is taking place.
**Education**

Try to educate family and friends about their loved ones’ difficulties. Key in cognitive rehabilitation is consistency therefore teach family, friends to adopt the same strategies that staff are using with the patient. Make sure community staff and care agencies receive a copy of the strategies you have implemented at handover.

**Executive Function**

Executive difficulties, also known as frontal lobe disorder or executive function impairment, occur as a result of an injury to the front part of the brain. These can be difficult to treat, partly because they are so varied and also because they often come with a lack of true awareness and insight. There are mixed reports in the literature about the prevalence of executive difficulty after stroke, however as most staff working in stroke services will know, it does affect a considerable amount of the patients we work with.

A patient may present with normal intellectual function and memory on formal testing. However, testing of pure executive function (discussed later) may highlight difficulty with problem solving, planning, organising and higher mental flexibility which will impact on general intellectual function *(see Frontal lobe history and tests summary sheet in the toolkit).*

The frontal part of the brain plays a key role in higher level functions including: motivation, planning, social cognition, inhibition, long-term memory, processing speed, speech production, taste and smell and intimate relationships.

**Motivation**

Usually presents as a difficulty in starting activity or wishing to engage in any activity. Patients will usually disengage with activities that they once enjoyed or may even disengage with loved ones. Rather than using the term motivation, it can be helpful to think about it as “initiation difficulties”. Often when people are said to have “low motivation”, it can be perceived quite negatively as it implies the person cannot be bothered, or does not want to engage in therapy. Often though, this lack of
motivation is a result of cognitive changes. It is important to note that low motivation can also be caused by low mood and anxiety.

### Planning

**Task:**
Imagine being asked to arrange a booking for 4 people at a local restaurant to celebrate a birthday. What steps would you need to take? List all of the things you would need to do. In order to successfully complete this task, you need to achieve the following:

1. Understand the request
2. Initiate the first and all subsequent steps, e.g. enquire about suitable times for guests, availability at restaurant etc., final booking
3. Maintain concentration to complete the task
4. Change arrangements dependent upon feedback from others. Double check special dietary requests.
5. Speak to the restaurant about the time and number of people attending
6. Contact each individual to ensure they know the time – memory, clear communication.

A night out with friends suddenly appears quite complex. Each of the steps described would be even more difficult to carry out for an individual with executive difficulties.

### Social cognition

Social cognition is about our understanding of social situations. Most of us know how to turn take in conversations. We generally do not interrupt someone who is speaking as it is socially unacceptable to do so. It is necessary for all of us to manage and change our responses dependent upon the feedback we get from our environment. Social cognition also means that we are also generally able to see things from another person’s point of view. This is very important as it allows us to empathise. If social cognition is affected after stroke, the
brain is less able to process sensory and environmental cues to gauge whether certain behaviours are appropriate.

The person may not be able to empathise, or may not observe the social norm. They might make quite blunt comments and appear very rude or uncompromising. They might also be dismissive to those important to them.

If this change in the person is very noticeable, it will often be reported by family and friends. However, some patients present with subtle changes, so we need to be aware of this.

**Impulsivity/Self Control**

Impaired executive function can also lead to risk taking behaviour, and a lack of self-control. For example, your GP told you that you need to adopt a healthy diet because you have high cholesterol. When you walk past the fish and chip shop, your first impulse is to buy a nice large portion, with extra chips on the side. At this point your executive functioning helps you to exert self-control, walk on and buy a salad instead. Someone whose impulse control has been affected would not be able to override their first impulse and instead buy the unhealthy meal. This is often of great concern, for example when a patient decide to cross the road without looking as they have spotted something of interest on the other side.

**Processing Speed**

One effect on executive function that Stroke often has is a general slowing down in processing speed. It may take people a long time to process new information. This slowness can sometimes be mistaken for a communication difficulty as people often take a while to respond.

**Speech production**

Patients might talk incessantly or talk much less than usual. Their language might be disjointed and bizarre in nature at times. They may also be less likely to engage in reciprocal and fluent conversational skills.
Intimate and/or sexual relationships

Dorsolateral frontal lobe damage reduces sexual interest and orbital frontal lobe damage can result in peculiar sexual habits. Individuals might become sexually disinhibited as they respond to internal feelings. Their difficulty is with regulating their feelings and responding appropriately to the social rules that they previously accepted.

Sexual difficulties after stroke are very common, however many patients will not come forward to talk about these. There is more information on this topic in the final section of this manual – difficult issues.

Loss of smell and/or taste

Patients may report a loss of smell or taste, or things might taste different to how they did before the stroke. One individual I worked with hated olives before he had a stroke, but following the stroke, they became one of his favourite foods!

Assessment

There are several screening tools available which you can use to assess certain elements of executive function. Two of these screens are the MMSE and the ACE-R.

You can find a copy of the ACE-III in the toolkit.

Executive function includes a broad range of skills. These functions can be tested in a number of different ways. Some of the most common forms of testing are listed below:

Letter fluency (FAS)

Ask the individual to name as many words as they can think of beginning with F in one minute, without repeating themselves and without giving you names. Repeat the task using the letters A and S. How many words did the patient produce? Were there signs of perseveration or memory problems? Did they use a strategy (looking around the room, going through the alphabet)?
There is an example of a letter fluency task in the toolkit.

**Category fluency**

This is similar to letter fluency but the patient is asked to list things which belong to a particular category, for example, list as many animals as you can think of in one minute.

There is an example of a category fluency task in the toolkit.

**Impulsivity**

This can be assessed with a simple tapping task: ask the person to tap twice when you tap once, and tap once when you tap twice.

**Trail making test**

An individual is shown a page consisting of numbers and/or letters scattered about. They are asked to make a trail, joining the numbers or letters in a consecutive order. The task can also be made more difficult by asking the person to alternate between numbers and letters, so for example their trail would look like this – 1, A, 2, B, 3, C, 4, D, 5, E and so on.

You can find a Trail Making test in the toolkit.

**Cognitive estimates tests**

The individual is asked questions which require them to make a rough estimation, for example, how tall do you think a postbox is? How long does it take to blow up a balloon? How long would it take to clean the windows at your house?

There are some example cognitive estimate questions in the toolkit.

**Planning tasks**

An example might be to give the patient a shopping list with a picture of a shop layout and ask in which order they would collect the items that they need. Do they go
for the items in order that they are listed? Do they do it completely randomly? Or do they collect the items in a more “thoughtful” order, for example getting all of the items from similar shelves/areas of the shop before moving on to the next items?

**There is an example of a shopping, planning task in the toolkit.**

**Writing**

Check for perseveration with words such as “seen” or “need”, or copying a 12 dot line.

**Abstract concepts**

One way of testing this is to ask an individual to identify similarities between simple pairs i.e. apples and oranges, table and chair. Alternatively, read a proverb out and see if the patient can understand the meaning behind it (e.g. “you can lead a horse to water, but you can’t make it drink”).

**You can find some example abstract concepts questions in the toolkit.**

Observation is the key when you are trying to assess difficulties with executive function. Try to understand the reasons behind behaviour change, reduced social skills etc. Think about whether neuropsychological testing would be useful for this individual at this time to support understanding and neuro-rehabilitation.
How can you help?

Goal Setting
In order to develop and maintain some level of awareness of difficulty, get feedback and help your client to develop goals. You can use the Goal Attainment Scale to do this (in the toolkit). This should be monitored carefully with consideration of emotional state of the person and psychological function, e.g. denial.

Even if a patient describes unrealistic goals they need to be noted as goals your patient has stated. Do not challenge these, but help your patient break down such goals into small steps. You may want to use motivational interviewing for this.

Environment

Structure and routine
For an individual with executive function difficulties, having some structure and routine to their day is very important. A simple way of achieving this is to ensure that they have a diary or calendar on which they can plan out their day or the week ahead.

Organised, calm environment
Sometimes people who are experiencing executive function difficulties say they feel like there is chaos and disorder going on inside their brain... the last thing they need then is to have chaos in their environment too. People may need more time to take things in, or they may be easily distracted by other stimuli in the environment. One of the things you can do to support their needs is make sure that their environment is calm and organised.

Limit overstimulation
Most people will admit to feeling a little overwhelmed after having a stroke. They have to get used to new sensations in their body and impairments where previously there were none. They also have a lot of new information to take in, and a different environment to deal with while they are in hospital. Be mindful of this, particularly
when someone is having difficulty with executive function. Overstimulation can be just as bad for rehabilitation as under stimulation.

**Paired external cues**

An example of this would be a song or melody which helps a patient with pacing while they are completing a certain task. For example, Gervin (1991) used songs with lyrics containing simple one or two stage commands to play while patients were getting dressed. By working to the pace of the song, and following the commands, individuals were able to improve the time it took to get dressed.

**Memory**

The human memory is very complex and because of this, a stroke can cause a wide range of problems relating to memory. The image below shows the different kinds of memory. As you can see, there are many different types of memory: short-term, long-term, memory for things we need to do in the future, and those for our knowledge of the past.
In this section we are going to explain those aspects of memory that are relevant following a stroke, with some examples of what might happen when the area of brain responsible for each is damaged.

**Anterograde memory**

When people have problems with their Anterograde memory, they may be unable to form new memories after their stroke. Their memory of past events, right up until they had the stroke might be perfect, but it can be extremely hard for them to remember new information. Problems with this type of memory can be partial or complete. Anterograde memory is sometimes called our “future memory” as it is also responsible for our ability to remember information which we will need in the future. An example of this would be arranging to meet a friend for a coffee and then forgetting to go. When someone has problems with their anterograde memory, they may start showing the following behaviours:

- Forgetting recent personal and family events (appointments, social occasions)
- Losing items around the home
- Repeating questions over and over again
- Inability to follow and or remember plots of movies or television programmes
- Deterioration of message taking skills
- Becoming increasingly reliant on lists

Relatively pure anterograde amnesia may be seen when there is hippocampal damage (often seen in herpes simplex encephalitis), which may be due to focal temporal lobe tumours or infarction.

**Retrograde memory**

This is our memory of past events and refers to our ability to remember all of the things that have happened to us – jobs we have had, holidays we have been on, past relationships. When someone has problems with their retrograde memory, they might have no recollection of things like:
• Historic events – such as the shooting of JFK, or the terrorist attacks on 9/11
• Where they live or where things are – they may get lost often
• How to complete everyday tasks – for example using a razor or making a cup of tea
• They may also not recognise their family and friends

It is often the case that both anterograde and retrograde memory loss occur in parallel, to differing degrees. This can make it very hard to assess patients and implement strategies to help them.

After stroke, we often see patients who confabulate and seem to be “making up” some weird and wonderful stories and memories. Their memories might be grandiose or delusional but confabulation is often caused by the mis-ordering and fusion of real memories which end up being retrieved out of context. This can make them sound unrealistic and often quite bizarre.

**Working memory**

This is our short-term memory and refers to memories of things that have happened within the last few seconds. For example, when being given a telephone number, I need to remember the sequence for long enough to write it down or dial the number.

Problems with working memory can lead to lapses in concentration and attention (losing your train of thought, wandering into a room and forgetting the purpose of the visit). These things are common and increase with age. They are also more common in those who are depressed or anxious. In isolation these memory deficits are of lesser concern.

**Semantic memory**

This is our memory for storing ideas, meanings and concepts. Patients with semantic memory breakdown typically complain of “loss of words”. Vocabulary diminishes and patients substitute words like ‘thing’. There is a parallel impairment in appreciating the meaning of individual words which first involves infrequent or unusual words. Word finding difficulties are also common in
anxiety and aging. However, in these cases they tend to be variable and are not associated with impaired comprehension.

Simply asking both patient and informant to give an overall memory rating out of 10 is often helpful. It is rare for truly amnesic patients to give themselves scores such as 0 or 1, although their spouse might. In contrast a patient whose semantic memory has been affected because of anxiety or depression will usually rate himself/herself very low.

**How to help**

A good assessment of the strengths and relative difficulties with memory is important. It would be silly for instance to use auditory strategies to help individuals remember if their verbal memory is impaired. If their strengths are with remembering visual information it is likely this is key to helping individuals retain and recall new information. Much of the rehabilitation that takes place in a hospital or community setting is compensatory.

**The Environment**

- Ensure the environment allows for routine and structure. This makes the cognitive load easier to manage and is more likely to support greater concentration/attention to task/material to remember

- Keep important items in the same place each time, for instance, keys near the front door

- Try to keep a timetable of activity so that routine can be remembered.

**External strategies**

- Prompts (these can be auditory prompts from external devises such as mobile phone, timer etc)

- You. Regular prompts from you to help reinforce new learning. Errorless learning is quite useful here, for instance if your patient is unable to retain information about day-to-day events, consistent and constant reminders in the early stages is helpful with a view to reducing this once learned.
• Diary or calendar system for appointments/medication

• Visual journal to recall events (e.g. photographs of events with written summary)

• Errorless learning to remember new names

• Labelling items or places to enhance ability to achieve independence

What strategies you use will be dependent upon the needs of your patient. For instance, if your patient is at university and required to learn a new theory this will require a different degree of strategy development compared with the patient who wants to remember the names of his/her grandchildren.

**Personality Change after Stroke**

For many stroke survivors and their family and friends, it is not the physical changes after a stroke that cause the most distress, but the personality changes. Of course not everyone will experience a change in personality after stroke, but for those that do, it can be quite devastating.

Commonly reported changes after stroke include:

• Becoming short tempered
• An increase in aggression/anger
• Increased anxiety and worry
• Low mood and/or apathy
• Increase in frequency of shouting/swearing
• Reduced patience, or less easy going nature
• Uncaring, unsympathetic attitude
• Making inappropriate comments
• Becoming easily frustrated
• Feeling paranoid about others’ opinions
• Increased irritability
• Reduced confidence
• Dissatisfied easily
There is a very thin and blurry line between personality, behaviour and emotions. Many of the above changes could come under all three of these headings but, ultimately, we tend to take people’s behaviour and emotions into account when we judge their character, or their personality. Anger is an emotion, or a feeling, but increased anger can lead to increased aggressive behaviour. If this becomes a regular occurrence, it may become part of a person, and we might label them as being aggressive or angry.

Many carers and family members of stroke survivors report big changes in the personality of their loved ones. Often they describe a caring, gentle, laid-back person who has become short tempered, aggressive and uncaring. If you consider the fact that a stroke survivor has experienced physical changes to their brain (often affecting personality), as well as the actual impact of the stroke on their emotions (for example, frustration from not being able to do everything they could before), it is not surprising that this is sometimes the case.

It can be extremely difficult to provide care and unconditional love/attention for someone who often seems ungrateful and treats you with little respect but this is what thousands of carers in the UK have to deal with every day. Ultimately, the better they understand the reasons for the changes in personality, the more ready they will be to accept them and realise that it is not necessarily something the stroke survivor can control. In fact, a lot of the time the stroke survivor is not actually aware of the changes, which can in itself cause problems as they do not understand what all the fuss is about!

Personality change after stroke is not something that remains static, and as with physical changes, there are often improvements/changes over time. Some people report seeing “glimpses” of the stroke survivor’s personality before their stroke, whereby every now and then they seem to be back to themselves for a few minutes or hours. Sometimes, over time these glimpses can become more and more frequent until the individual is almost the same as they were pre-stroke.
In many cases, distant friends and relatives may not notice changes in personality or behaviour, it may only be the stroke survivor's main care giver, or partner who spends enough time with them to recognise the small things that are different. This can be incredibly frustrating as the carer may feel that others think they are exaggerating or making things up, when in fact they just know the stroke survivor better than anyone else and therefore are best placed to spot changes. Also, if you think about your own relationships with friends and family – how often do you argue with friends, aunties, uncles or even your parents? Compare that to how often you argue with your partner and you can see that we do tend to share more of that side of ourselves with those closest to us – probably because we know we can get away with it!

Ultimately, there is no way for us to “measure” personality change. As we do not know who is going to have a stroke, we can’t measure pre-stroke personality so that we are able to compare it to post-stroke personality. Personality is also quite subjective, and means different things to different people. Generally when someone is talking about an individual’s personality, they will talk about behaviour, mannerisms, characteristics, feelings and everything else that makes somebody the person they are. However, the personality of an individual will in itself affect how they view other people. This can make it extremely difficult to gauge what has actually changed and what is simply perceived to be a change.

For example, someone who has recently become a carer may find they are feeling incredibly tired and over worked, as well as being vulnerable to experiencing low mood, anxiety and depression. These factors in themselves will have a huge impact on how they view the behaviour and actions of the person they are caring for. There may be additional issues such as grief and loss to deal with as a carer too.

Clearly working with personality change is not an easy task, but some of the first steps you should take if someone is reporting a change in personality are as follows:

**Rule out emotional disorders**

Depression or low mood can cause any number of changes in behaviour and often these are mistaken for a change in personality. Feeling restless or irritable can be a symptom of depression, as can
persistent “sad” thoughts, loss of interest in activities and feeling tired or fatigued. If someone is experiencing symptoms like these, it is important that depression and other mood disorders are ruled out before you put it down to personality.

Similarly, anxiety can cause people to worry a lot and to “make a mountain out of a molehill”. If someone seems to be getting stressed or worrying about something which ordinarily wouldn’t have bothered them too much, it could be because they are dealing with an anxiety disorder such as GAD (Generalised Anxiety Disorder). This may lead to them becoming agitated and creating arguments or disagreements over seemingly small things.

**Rule out sleep problems**

At one time or another, most of us will have experienced difficulties with sleeping. Whether due to internal causes or external causes (such as a new baby), you will know how grouchy you feel after several nights of poor sleep. Generally when we are tired, we are at our most irritable and may find the tiniest little thing frustrating or annoying. A lack of sleep can also make you feel more impatient than normal, often resulting in short temperedness which you can take out on your loved ones.

It is quite usual for sleep patterns to be affected by a stroke, whether this causes someone to sleep more or less than they ordinarily would. It is therefore important to rule out any sleep problems that could be affecting an individual’s mood before putting things like irritability or impatience down to personality change.

Look in the toolkit for the Pittsburgh Sleep Quality Index (PSQI), Sleep Diary and Information Sheets about sleep hygiene.

**Are they receiving enough support?**

Being unable to do things that at one time came easily to you can be incredibly frustrating. Having the correct support in place can greatly ease this frustration however, and make
things that little bit easier. If someone is struggling physically, or has been left with a
cognitive impairment that they are finding it hard to cope with, ensure that they have
the appropriate support in place.

Without the correct support, people can quickly become frustrated and impatient with
both themselves and those around them. Imagine if one day you woke up and it took
you three or four times as long to do everything that you would normally do in a day –
you too would probably feel frustrated. Having the right support in place can make
things better, easing frustration and pressure and making life that little bit more like
“normal”.

It is important to take the above possibilities into consideration when thinking about
why someone’s personality has changed, however in many instances, damage to the
brain caused by stroke will genuinely alter an individual's personality and behaviour.
Sometimes when this is the case, we are more limited in what we can offer. Apart
from giving support to the stroke survivor and their family/friends, we might be able to
reduce the extent of the problem. Suggestions include the following:

**Talk to the stroke survivor**

As previously mentioned, often when an individual’s personality changes after stroke, the stroke survivor may genuinely not realise
that they are any different to how they used to be. If family and
friends skirt around the issue and do not mention it for fear of
upsetting the person affected, they may never realise that there is
a problem. Of course in the early stages following stroke, this may be the best course
of action, especially as things might settle down and become more “normal” in time.
However, further down the line, if the stroke survivor is not aware of the issue, they
will be unable to work towards solving it.

The person closest to the individual should raise the topic, and explain in a calm, un-
blaming manner how they feel that the person’s personality has changed. They
should also be prepared with examples of uncharacteristic behaviour that they can
use to show the stroke survivor what they mean. Depending on the situation, it may
also be beneficial for a medical professional to explain to the stroke survivor the
ways in which stroke can affect personality, so that they understand it is a common
effect of stroke.
How the individual reacts to being told will vary from person to person, but even if they shrug it off and act as though they do not care, they most probably will have taken the information on board which may allow them to spot change in themselves in future. Hopefully though, they will appreciate being told and will try and work with their carer/relative to seek help.

**Educate**

If a stroke survivor, or a relative/carer is reporting personality changes, they should be provided with information about personality change after stroke, including how and why it occurs. It is particularly important that relatives are given this information so that they can understand not to take any negative changes personally and realise that the stroke survivor is not necessarily able to control their actions or behaviour in some instances. Understanding this is likely to make them more tolerant of the behaviour, and be more patient with the stroke survivor.

One of the most common complaints after stroke is that the individual seems to have lost their “filter” – they say things without thinking them through first, no matter how inappropriate, rude, or offensive! In some circumstances, people find this quite funny and will laugh at the comments, in other circumstances however, it can be very embarrassing and even upsetting to other people (especially if they do not understand the reason behind it). Unfortunately, if friends and family laugh sometimes, and get angry at other times, it gives out quite a mixed message and the stroke survivor is unlikely to take the problem very seriously if they do not feel that others are taking it seriously. It is therefore important that everyone provides the same kind of information and inappropriate behaviour is discouraged no matter what the circumstances.

**Communicate and provide information**

As previously mentioned, in some cases it will only be the main caregiver or partner of the stroke survivor who witnesses changes in personality. This can make it very hard to get others to take the problem seriously and means that the caregiver will often receive little support from the wider group of friends and relatives. It can help
for a health professional to sit down with friends and relatives and explain a little about personality change after stroke, ensuring they realise that it is a common issue and that it will often not be immediately obvious to those who do not spend day in and day out with the stroke survivor.

**Use recordings**

Have you ever watched a video or heard a tape recording of yourself and had a completely different reaction to what you were doing than the one you had at the time the recording was made? For example, I have recorded a training session I delivered which I thought at the time went terribly! Looking back at a video of the training however, it actually seemed to run quite smoothly and I realised that I had been overly critical of myself. Sometimes looking back over something gives us the opportunity to view it as a third person and get a better perspective on what actually happened.

This can be a particularly helpful method to use with a stroke survivor when they do not realise that they are behaving differently, as sometimes watching their behaviour back can help them to see how things really unfolded. Generally the best person to do this is the carer/partner who will have an idea of the situations which tend to clearly show a change in personality or behaviour. Advise them to try talking with the individual first, to explain their concerns and if this does not work, they should ask the stroke survivor for permission to use a video or audio recording to demonstrate what they mean. Often, upon watching the video they will be surprised by what they see but are usually more ready to accept it and seek help/support for the issue. It goes without saying that this should not be done without express permission from the stroke survivor.

**Mental Capacity**

Mental Capacity means the ability to make a decision (Mental Capacity Act, 2005). The Mental Capacity Act (2005) protects any vulnerable individual over the age of 16 whose capacity to make a decision at a particular time is affected by factors such as stroke, dementia, a learning disability or a mental health illness. The Act applies to all people (staff, carers, family and other professionals) making decisions for, or acting in connection with, those individuals who lack the capacity to make these decisions for themselves.
Capacity to make decisions can fluctuate over time, or can vary according to the type of decision that needs to be made. The Mental Capacity Act states that capacity should always be assumed, and unwise decisions do not necessarily mean a lack of capacity. Capacity is decision specific. This means that just because a person may be deemed lacking capacity to make decisions over one aspect of their lives, does not mean they lack capacity to make decisions over other areas of their lives. Doubts as to a person's capacity to make a decision may occur because of:

1. The way a person behaves
2. Concerns raised by someone else
3. The individual's circumstances.
4. An impairment / disturbance of mental functioning

According to the Act, two important questions must be answered before a decision can be made as to whether an individual has capacity to make a decision:

- Is there an impairment of, or disturbance in, the functioning of the person's mind or brain?
- If so, is the impairment or the disturbance sufficient to cause the person to be unable to make that particular decision?

It is important to remember that most people we work with will be able to make most decisions, even with a label (i.e. learning disability) or diagnosis (i.e. dementia).

Decisions and actions carried out under the Mental Capacity Act (2005) should be tested against 5 key principles. These principles act as benchmarks for decisions to be made on someone else's behalf.

**Five Key Principles of the Mental Capacity Act (2005)**

1. A person is assumed to have capacity, unless it is established that they do not.
2. a person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
3. a person is not to be treated as unable to make a decision merely because he makes an unwise decision.
4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be effectively achieved in a way that is less restrictive of the person’s rights and freedom of action.

All practicable steps should be undertaken to support the person in making the decision, including providing all relevant information, simplifying information, outlining the benefits, risks, and consequences of certain decisions and actions, enhancing the person’s communication and ensuring that they are made to feel at ease. If the support required for the process does not enable a person to make a particular decision, a capacity assessment is usually required (Church & Watts, 2007)

**Assessment**

The process of the assessment has to be clear and accountable. The process usually requires input from a range of systems in the person’s life that provide support and should include the person, their carers, and their families. If there is no family or carer who is authorised to make decisions for that person, an Independent Mental Capacity Advocate (IMCA) may be assigned, if there are important decisions around accommodation changes or medical treatments. Anyone conducting a capacity assessment should keep adequate records detailing the grounds on which a person was deemed to lack, or have capacity.

Please see flow chart guide in the Toolkit.

If there is a question about mental capacity the decision to carry out a formal assessment of this should be decided y the treating team and appropriate clinicians involved.

A clinical interview with the person must examine the person’s ability to meet all four criteria of capacity, as defined by the Act. The Mental Capacity Act (2005) indicates
that a person is unable to make their own decision if they cannot do one or more of the following four things:

1. **Understand** the information given to them.
   Anyone carrying out a capacity assessment should ensure that the information presented to the person is relevant, simplified, accessible according to that person’s needs, and outlines the benefits and risks to themselves and others.

2. **Retain** that information long enough to be able to make a decision.
   If the individual struggles to retain the information, diaries, video and voice recorders can be used. If the decision made is forgotten the person can still found to have capacity if, when, taken through the same process at a later time, they come to the same decision.

3. **Weigh up** the information available to make a decision.
   Any difficulties in weighing up the information may be overcome by simplifying the choices. If the person cannot choose between the two alternative risks, even with support, then they will fail the test of capacity.

4. **Communicate** their decision through talking, using sign language, pictures, or other methods of communication. Every effort should be made to find ways of communicating with someone before deciding that they lack capacity to make a decision based solely on their inability to communicate. Also, you will need to involve family, friends, carers or other professionals who may know the person well, and support them in the communication process.
The decisions as to whether or not a person has capacity must be made on the balance of probabilities – is it more likely than not that the person lacks capacity? Any decisions should be made in the person's best interests and should be the least restrictive solution possible.