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Welcome

The effects of a brain injury can range from almost insignificant to catastrophic. Some will be clearly evident, others more subtle. They may be permanent. Or not. Such wide-ranging outcomes mean that issues of capacity and consent are particularly pertinent for those affected by brain injury and, of course, for their carers.

The ability to make decisions is defined by the Mental Capacity Act 2005, which in 2014 was criticised in a House of Lords review for not living up to the expectation that it would empower even the most vulnerable members of society to make decisions for themselves.

In this edition of Brain Injury News, our headlining article by Patricia Wass of Foot Anstey, examines how the Mental Capacity Act works in practice and considers whether it is successful in placing the individual at the centre of the decision-making process.

We also take a look at the role of the deputy and the need for objectivity in making “best interest” decisions on behalf of others (page 7), at the sensitive topic of consent in respect of end of life decisions (page 18), and at the key benefits of lasting powers of attorney which enable individuals to appoint someone to look after their affairs if it becomes necessary (page 17).

Turn to page 11 for commentary on a recent landmark decision that has updated the law on consent and fundamentally changed the relationship between doctor and patient.

The complex and fluctuating effects of some injuries can make assessing an individual's capacity particularly tricky (page 12), and even seasoned professionals can make mistakes with assessments as we see on page 10. Page 14 reveals how social work professionals are often called upon to assess both capacity and ongoing needs, and we also find out how case managers play a vital role in supporting clients to live the life they choose (page 9).

We welcome your views on these topics and any brain injury-related issues, and are grateful to the many people who have contributed to this edition. Please visit our website to find out more about the Brain Injury Group or call us on 0800 612 9660 if you think we can help you.

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The Brain Injury Group, a not-for-profit community interest company, is a network of specialist brain injury solicitors and other professionals with proven experience of supporting those affected by brain injury. Our aim is to provide a gateway to support, information and advice for brain injured people, their families and carers.

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Follow us on
The Mental Capacity Act: a visionary piece of legislation?

Patricia Wass of Foot Anstey discusses the practical application of the Mental Capacity Act, explaining the importance of its basic principles: that the focus of decision-making must be centred around the individual who may lack capacity and the importance of never making assumptions.
The Mental Capacity Act 2005 (the Act) sets out an integrated jurisdiction for the making of decisions about personal welfare, healthcare and finances. The House of Lords undertook post-legislative scrutiny of the Act in 2013, publishing its report in March 2014.

The preface states:

“\textit{The Mental Capacity Act was a visionary piece of legislation for its time, which marked a turning point in the statutory rights of people who may lack capacity... with the potential to transform the lives of many. However, its implementation has not met the expectations that it rightly raised. The Act has suffered from a lack of awareness and a lack of understanding... The empowering ethos has not been delivered. The rights conferred by the Act have not been realised.”}"

The report concluded there was much work to be done if the “transformative power” of the Act was to be felt by all those for whom it was intended. With 39 recommendations, the report also included a challenge to all professionals:

“A fundamental change of attitudes among professionals is needed in order to move from protection and paternalism to enablement and empowerment.”

The complexities of decision-making

In assessing capacity, the Act is unequivocal in its fundamental principles (see box-out on page 8) and a Code of Practice provides guidance to those working with and caring for adults who may lack capacity, to help them comply.

Alongside the basic principles, the Act states that a “\textit{person lacks capacity in relation to the matter if at the material time he or she is unable to make a decision for himself or herself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the brain or mind.”} It does not matter whether the impairment is permanent or temporary, and assumptions about a person’s capacity must not be based on age, appearance, condition or aspect of behaviour.

Capacity is both decision and time-specific. An individual may lack capacity to make decisions at one time, but have the capacity to make the same decision at another, or they may be unable to make a decision regarding one matter but have capacity to make a decision about something different at the same time. For example, they may lack capacity to administer their property and finances, but have requisite testamentary capacity to prepare a Will.

Capacity is ultimately a legal concept and the understanding of an individual will depend on the complexity of the relevant information and the legal test. It can be enhanced by the way explanations are given. A person should always be assessed at their highest level of functioning and practical steps should be taken to help them make the decision. It is also important to create the best environment for the assessment.

The Act sets out a two-stage test to establish capacity: a diagnostic test that can depend on the opinion of a clinician, and a functional test, which states that a person is unable to make a decision for themselves if they are unable to carry out the following:

(a) to understand the information relevant to the decision
(b) to retain the information
(c) to use or weigh the information as part of the process of making the decision
(d) to communicate their decision (whether by talking, using sign language or any other means)

If further information is provided, it may help an individual make the decision – even if they can only retain the information for a short time. That information needs to consider the reasonably foreseeable consequences of deciding one way or the other, or failing to make the decision.

If someone makes a decision about medical treatment that appears irrational, it doesn’t mean they lack capacity, as long as they understand the reality of their situation. For example, an individual may refuse a blood transfusion on religious grounds. This would not be considered a result of lack of capacity, as they understand the reality of their situation and the consequences. However, if someone with anorexia, who is malnourished, rejects treatment because they refuse to accept their condition, they may be considered incapable because they do not fully understand the reality of their situation.

There are some decisions that can never be made on behalf of someone who lacks capacity, such as marriage or civil partnership, divorce, sexual relationships, adoption and voting, because these are either too personal or because other laws govern them and the Act does not change this.

Always in their best interests

The overriding principle when making a decision for someone who lacks capacity is to consider their ‘best interests’, with checklists and criteria to ensure this principle is followed.

In some cases, a formal assessment of capacity may be required, possibly to establish that an individual comes within the jurisdiction of the Court of Protection or if there are legal consequences of a finding of a lack of capacity (eg. in settlement of damages following a personal injury claim). Professionals may need to be involved in formal capacity assessments if, for example, the decision is complicated or has serious consequences, if the person has a disabling head injury, or has fluctuating or borderline capacity.
The following questions must be considered:

1. Is there a general understanding of what the decision is and why they are being asked to make it?

2. Is there a general understanding of the consequences of making, or not making, the decision?

3. Is the person able to understand and weigh up the information relevant to the decision as part of the process of arriving at it?

Assessments and decisions must be recorded in detail and formal reports or certificates of capacity are often required for use in legal proceedings. In carrying out the assessment the determination of what is in the person’s ‘best interests’ is vital. It may be that the decision can wait until the person can give consent if they are likely to regain capacity at a later stage. The person should be involved in the decision as much as possible and issues they would take into account if they were able to make the decision themselves including religious and moral beliefs, must be identified. These would be based on views the person may have expressed previously as well as insight from relatives or friends.

**Consent for medical treatment**

All cases and day-to-day decisions for vulnerable people are made on the specific facts of the case and the decision that must be taken. For serious medical treatment where capacity to give consent is an issue, the Court must be involved. Such situations include:

- sterilisation for contraceptive purposes
- donation of organs or regenerative tissue, eg. bone marrow
- withdrawal of nutrition and hydration from someone in a permanent vegetative or minimally conscious state

The Office of the Public Guardian provides guidance (OPG603) setting out a number of case scenarios where a decision on capacity is required and how best to assist the person making it.

**Visionary legislation?**

To a degree, the visionary nature of the Act has been somewhat stifled because the practicalities have made it cumbersome to administer. The complex processes within the Deprivation of Liberty framework in particular were criticised in the report and the administrative burden of the Act has undoubtedly caused delays in the Court of Protection, making timely decisions difficult.

Administration has also added additional expense: legal practitioners can no longer get guidance and a directions order in response to a letter, application fees are required to support individual Court orders, and more capacity assessments are being commissioned than ever before.

The publication of (anonymised) judgments provides useful guidance for practitioners, but has also led to criticism in the press resulting in a misconception that the Court of Protection is a ‘secret court’, which is not correct. Anonymity is intended to protect the vulnerable people concerned, and the Court does good work to protect those unable to protect themselves.

Prior to the Act, I believe many professionals may have assumed incapacity for their clients without carrying out the assessments now requisitioned as a matter of course. The post-legislative scrutiny addressed many issues, providing a wake-up call to those working in the area of determining capacity – not least a timely reminder that the vulnerable person must remain at the centre of the decision-making process and be supported to make decisions for themselves wherever possible.

Continued on page 6
CASE STUDY

The changing nature of capacity

I act as the Court-appointed deputy in respect of the property and finances of a man in his thirties who suffered a brain injury in a motorbike accident. His cognitive functioning, including memory and executive skills was affected, and he became irritable, critical and impulsive. It is unlikely he will ever have gainful employment, and a significant personal injury claim was made after the accident.

At the time of the accident, my client was married with three sons, with another son from a previous relationship. Unfortunately, pressures at home led to him separating from his wife, so we had to instigate a number of capacity assessments on his behalf.

He lives independently with daily support workers and although he has compromised capacity in some areas, he is able to be involved in many decisions that affect him. For example, an assessment specific to making a Will determined significant testamentary capacity and we put a Will in place that reflected his instructions.

When two years ago, he and his wife intimated they wanted to divorce, we requested a capacity assessment in respect of the following:

- his ability to provide instructions in relation to matrimonial proceedings
- his understanding of divorce
- his capacity to conduct proceedings in relation to matrimonial financial matters

The clinical neuropsychologist who undertook the assessment said he struggled to distinguish between the role of his deputy and family law solicitor, and that he confused the legal processes of his personal injury claim and divorce proceedings. At that time he could not explain the difference between divorce and separation, was unsure about proceeding, and was disengaged regarding matrimonial financial matters. The assessor concluded that he did not have sufficient capacity in respect of the matters listed.

The assessments were recently repeated, producing a different result, demonstrating that issues relating to capacity can be time-specific and decision-specific. This time, the same assessor advised that the client did have capacity in respect of instructions relating to matrimonial proceedings and understanding of divorce. However, he did not have capacity to conduct proceedings in relation to matrimonial financial matters.

The assessor suggested a number of practical ways to support him in taking divorce proceedings further: carers to attend meetings with the solicitor and be involved in telephone consultations, taking notes that could be reviewed in detail and going through correspondence with him, which he was asked to summarise to demonstrate understanding. The solicitor was advised that the client was able to make abrupt judgements when agitated, but also able to weigh up factors when given key facts and time to calm himself.

It is important that capacity is established in order to proceed with the divorce because the Act does not allow decisions regarding marriage, divorce and other intimate family matters to be made on someone else’s behalf. Here, all the Court can do is advise whether the person may have capacity or not relating to marriage or divorce and make a declaration to that effect – it cannot consent to a marriage or divorce going ahead.

Patricia Wass is a consultant solicitor, leading Foot Anstey’s Court of Protection team. She is one of only 68 professionals appointed nationwide to the panel of approved deputies created by the Office of the Public Guardian (OPG).

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The Mental Capacity Act (MCA) replaced the old style ‘receiver’ with a deputy, appointed to ‘step into the shoes’ of someone lacking mental capacity and take decisions on their behalf. Adrian Mundell of Ashton KCJ considers the fundamental importance of this role, how they are chosen and what their duties entail.

A deputy is appointed by the Court of Protection to manage the affairs of an individual who, due to lack of mental capacity, is unable to manage their own. They can be appointed for ‘Property and Affairs’, giving them responsibility for someone’s money and assets, or for ‘Health and Welfare’, where they are responsible for welfare and care decisions. This article focuses on the role of the ‘Property and Affairs’ deputy, which is the most common appointment.

Family member or professional?
A deputy is usually appointed where a person has lost mental capacity and has no plans in place to cover this eventuality, such as a Lasting Power of Attorney or one of the old Enduring Powers of Attorney. The majority of individuals that the Court of Protection is responsible for are elderly, and a family member is often chosen to act as deputy. However, in a case involving a substantial damages award, Senior Judge Lush (Senior Judge of the Court of Protection) indicated that the Court of Protection prefers professional deputies rather than family members to be appointed in all but exceptional cases – at least for the first few years after settlement (BABICM newsletter, Autumn 2011). There may also be a practical problem with a family member not being able to get the appropriate level of security bond required by the Court if it has been set at a high level – which is often the case with a large damages award.

Any deputy, whether professional or lay (non-professional), has a duty to comply with the MCA and its principles, which are listed on page 8. The key principle that must guide any deputy’s actions is that of acting in the best interests of the incapacitated person. This can mean setting aside personal views and preferences (and prejudices) in order to step into the shoes of the person for whom you are making the decision. This can prove difficult where a family member is acting as deputy, particularly if there is a potential conflict of interest.

Caring consultation
So how does a deputy act in the best interests of an incapacitated person? One requirement of the MCA is to consult. Even though the individual has been deemed to have lost mental capacity, they may be able to express opinions on certain matters and these must be taken into account as far as possible.

Continued on page 8
Capacity can fluctuate, which means the deputy may be able to speak with the individual at different times. Consultation should also happen with those who are closest to the individual — usually family — but friends, care staff or other professionals can also provide useful insight into their wishes or views. A deputy should also give consideration to a person’s beliefs and decisions prior to the loss of capacity, which indicates what they view as important and the likely course of action they would have taken were they able to now decide.

The role of a deputy varies from client to client. A lot of work is required, for example, where a person has lost capacity due to an acquired brain injury and a claim is being pursued. In such complex cases, the support of a professional deputy can be hugely beneficial both for the individual affected and their family. Caring for someone with life-changing injuries is inevitably very challenging for the family, and managing a substantial damages award can be an unwelcome distraction from supporting their loved one.

A deputy may be called upon to deal with:

- making applications to the Court of Protection
- preparing and submitting tax returns, preparing annual report and accounts for the Office of the Public Guardian
- dealing with the employment of care teams including payroll, contracts, pension auto-enrolment and employment disputes
- setting and monitoring budgets and ensuring availability of funds to meet a person’s day-to-day needs
- arranging the investment of a damages award through a specialist independent financial adviser
- payment of bills and liaising with family over the best way for these to be dealt with
- liaising with case managers and other professionals in respect of care teams, therapists and other needs
- supporting individuals and families in the process of buying new, appropriate properties including the conveyancing process and the paperwork it generates
- working with architects and others to adapt properties as required
- consideration of statutory funding availability and dealing with benefits applications
- applications to the Court

This list provides only an indication of what being a deputy involves. The reality is that finance touches most areas of our lives, so the work of a deputy can be extensive and wide-ranging.

Where an injury claim is ongoing, it is possible to recover the costs of a professional deputy, and these costs should be included within the schedule of loss.

In summary, the role of the deputy is to step into the shoes of the person who has lost mental capacity and to take decisions on their behalf, which will cover many areas of their life. It is key to remember that when making a decision for an incapacitated person it should always be in their best interests. This can depend on many factors, but wherever possible a deputy should consult with others.

**Mental Capacity Act: the basics**

The Mental Capacity Act 2005 (the Act/MCA) came into force in October 2007 and is designed to protect and empower vulnerable individuals who aren’t able to make their own decisions, and enable people to plan ahead to a time when they may lose capacity.

It deals with the assessment of a person’s capacity and acts by their carers, and enshrines in statute best practice and common law principles concerning those who lack mental capacity.

**Five key principles govern the practical implementation of the Act:**

1. **The starting point is that a person should always be assumed to have capacity to make a decision until it is established they do not.**
2. **Before it is established a person cannot make a decision, every step should be taken to help them make that decision. This may include taking time to explain and discuss things, using props to help them to understand etc.**
3. **Just because someone makes an unwise decision does not mean they are incapable of making a decision. Everyone is entitled to make what might be seen as an unwise or eccentric decision.**
4. **Every decision that is taken on behalf of a person must be taken in their best interests.**
5. **If options are available, you should always seek to take the least restrictive option for the person’s rights and freedoms.**

The Act is of particular interest to those affected by brain injury or their carers. Many people who have suffered a brain injury might appear perfectly “normal” when in fact they face a range of complex, sometimes subtle problems that collectively can be devastating. Assessment of their capacity to understand the decisions they may be asked to make or that will affect them can therefore be extremely difficult and the results can fluctuate.

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**Adrian Mundell** is a Partner at Ashton KCJ solicitors and heads up the Court of Protection team, which specialises in managing the affairs of clients who are in the process of making an injury claim or have received a damages award.

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AshtonKCJ
Getting the message across: the role of the case manager

A brain injury often impacts on an individual's ability to make day-to-day decisions, from issues of care to financial matters. Independent Living Solutions highlights the vital role that case managers play in supporting individuals to make decisions for themselves.

The Mental Capacity Act (MCA) states that in order to make an informed decision, an individual must be able to understand relevant information, retain that information long enough to be able to make a decision by weighing up options, understand consequences and then communicate their decision. Aided by other professionals, such as speech and language therapists who can advise on how best to communicate with individuals with cognitive or communication difficulties, the case manager’s role is to ensure that information is delivered in such a way as to enable the individual to understand and make an informed decision.

Leanne’s story

Leanne sustained a brain injury in a road traffic accident as a child. Overwhelmed by the need to make decisions regarding her care and rehabilitation, her case manager felt Leanne’s lack of confidence stemmed from a need for better knowledge and understanding of her options. Over time, her case manager developed flexible techniques to enable Leanne to have a greater understanding of the options available. By revisiting information in different ways – sometimes using Leanne’s interest in the internet, creating a picture book, breaking down each piece of information into manageable chunks – Leanne was able to make informed decisions.

Leanne’s primary goal was to walk unaided, but she was unwilling to take part in rehabilitation therapy. However, she gained a greater understanding of the positive outcomes of physiotherapy when information was presented to her in various different ways and she subsequently decided to engage in therapy. She now uses a walker indoors and is delighted with her progress.

We often work with clients that have capacity to make certain decisions, but who routinely make decisions that others might consider unwise. One of the fundamental principles of the MCA is that individuals are entitled to make those decisions and live the life they choose, in which case we support that client to ensure they are aware of both the risks and the consequences.

Tony’s story

Tony is a budding DJ with a brain injury, attending gigs in the UK with the help of his friends. Keen to try his hand working in Ayia Napa, Tony couldn’t see the potential difficulties that concerned his support team. In accordance with the principles of the MCA, his case manager agreed with what some may consider an unwise decision on a ‘best interests’ basis. But by implementing plans to minimise the risks, Tony was able to achieve his ambition.

Many of our clients have Court-appointed deputies to help manage their property and affairs. As case managers and as part of a care team, our job is to support people who have had a brain injury, providing them with the right information so they are able to make decisions – and achieve their goals.
The Mental Capacity Act (MCA) aimed to provide legal and medical practitioners with clear guidance on the assessment of capacity with a two-stage test. Yet there continues to be confusion around the process and it’s not uncommon to find different outcomes from two assessors presented with the same evidence. Tim Farmer identifies the six most common mistakes practitioners make when assessing mental capacity.

**Not correctly identifying the decision**
The key to a good assessment is correctly identifying what the decision is to be addressed. Getting it wrong, or making it too general often leads to a host of other problems, most notably the wrong outcome.

**Asking the wrong questions**
Few professionals called upon to assess capacity understand that it is up to them to ascertain the threshold of understanding required to demonstrate capacity. Setting the threshold means it is also their responsibility to determine the information required and subsequently the questions necessary to ascertain capacity.

**Using the wrong test**
Many practitioners still use the Mini Mental State Exam – actually the wrong one to determine capacity – and do not fully understand the complex interplay between case law and the Mental Capacity Act. There are also certain issues not covered by the MCA, and instances that require other legal tests or a combination of tests. Not using the correct tests in the first place often means the client has to undergo further assessments to rectify the mistake.

**Clinicians make moral rather than clinical decisions**
Family members – or their representatives – regularly call on us to challenge assessments where the outcomes reflect what the assessor felt would be best for the individual rather than on the ‘best interest’ requirement of the law. Unfortunately, as assessors we are rarely privy to all the objective facts and it is not uncommon for practitioners to become emotionally involved.

**Assuming a lack of capacity**
The presumption of capacity is clearly identified as one of the five principles of the MCA, yet health care professionals regularly assume a lack of capacity based on the individual’s diagnosis or presentation.

**Failure to validate the information given**
Poor referral forms and not taking the time to fully explore an individual’s circumstances often result in other professionals having incorrect or inadequate information with which to validate an individual’s responses. If you can’t validate the information the client is giving you, how can you accurately assess if it is correct?

Tim Farmer is a registered mental health nurse, managing director of TSF Consultants and an acknowledged expert in the field of mental capacity.

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Mrs Nadine Montgomery brought this action in the Court of Session in Scotland on behalf of her son, Sam+. Mrs Montgomery is diabetic and of small stature. It is well known that diabetic mothers can give birth to larger than average babies, which gives rise to a risk of shoulder dystocia, where the baby’s head is delivered but the shoulder becomes stuck. That is what happened to Sam. As a result, he suffers from cerebral palsy.

Whilst Mrs Montgomery had asked in general terms about the risks of giving birth naturally, she did not ask specifically about shoulder dystocia. Had she done so, the consultant would have told her about it. And had an elective caesarean section been requested by Mrs Montgomery, it would have been offered and Sam would not have been injured.

A ruling earlier this year established the duty for all health professionals to take reasonable care to ensure patients are made aware of all material risks so they can make an informed choice over treatment. Fred Tyler represented the family involved in this landmark case on consent, which has significant implications for the medical profession.

The doctor remains able to withhold information on risks if disclosure would be seriously detrimental to the patient’s health or in an emergency situation.

Many doctors will be unhappy with the decision, while others will take it in their stride. As the Supreme Court said in its decision: “This may not be welcomed by some healthcare providers; but the reasoning of the House of Lords in Donoghue v Stevenson [1932] AC 562 was no doubt received in a similar way by the manufacturers of bottled drinks.”

A bench of seven judges was convened in the Supreme Court as it was being asked to overturn the case of Sidaway v Board of Governors for Bethlem Hospital & Others [1985] ACV 871. Essentially, Sidaway decided that in relation to advice, as well as diagnosis and treatment, the test to be applied was whether or not the doctor had acted in accordance with a practice accepted as proper by a responsible body of medical practitioners. The Appellant argued that the appropriate test was a patient-centred test.

**Material risk: what’s reasonable?**  
The Supreme Court accepted that the appropriate test is patient-focused: the doctor has a duty to take reasonable care to ensure that the patient is aware of any material risks involved in any recommended treatment, and of any reasonable alternative treatments. Whether or not a risk is material depends on whether a reasonable person in the position of the patient would be likely to attach significance to the risk, or the doctor should reasonably be aware that the particular patient would attach significance to it. This coincides with Guidance issued by the General Medical Council dating back to 1998. The test of the ordinarily competent doctor no longer applies to the issue of consent.

Patients are no longer required to ask specific questions about the risks (of which they may be ignorant) and the onus is on the doctor to spell out those risks if they are material to the patient concerned. Doctors will be required to carefully record in the patient’s notes what was discussed regarding treatment and risks.

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* Refers to the famous “snail in the bottle” case from which the modern legal interpretation of negligence emerged: it established the principles of one person owing another a duty of care, and foreseeability.
Thinking straight: Assessing complex mental capacity

When a brain injury results in limited communication and inconsistent responses, an assessment of capacity for any given decision can be far from straightforward. Dr Jessica Fish and Dr Sarah Crawford present a case study revealing how assessors determine which decisions a patient with complex injuries is capable of making and which decisions they are not.

The Mental Capacity Act specifies the functional components of decision-making as understanding, retaining, and using relevant information, and communicating the resulting decision. If a person lacks ability in any component, as a result of an impairment of mind or brain, they are considered to lack capacity. That sounds straightforward enough, doesn’t it?

At the Royal Hospital for Neuro-disability (RHN) however, we work with many patients who may have limited communication methods, significant cognitive impairment, or show inconsistent responses over time and across contexts. In these circumstances, assessment of mental capacity can be complex, involving considerable time and customisation of procedures.

A further complicating factor is when patients have the ‘building blocks’ for decision-making, but additional difficulties prevent a robust ‘structure’ being formed from them, which is illustrated in the case study opposite.
CAROL’S STORY

Carol was 36 when she suffered two strokes that left her unable to use her left arm or leg, or to swallow safely. She uses a wheelchair and obtains all hydration and nutrition from a PEG tube. While at the RHN, Carol expressed her intention to return to her previous accommodation on discharge and to eat a normal diet – both against clinical advice.

We assessed her mental capacity to make these decisions in a process comprising standardised cognitive testing and a set of assessments designed specifically for this case. We examined decision-making ability at a theoretical or verbal level using interviews and vignettes, and also at a behavioural level using a bespoke functional task directly relevant to the decisions in question.

The cognitive assessment showed that Carol’s intellectual, memory and executive abilities were within normal range. This meant she likely had capacity to make many decisions and could certainly participate in complex decision-making. In the verbal assessment of decision-making, Carol was able to learn the appropriate responses and to provide them consistently over several sessions.

In the functional task, which presented a variety of safety challenges within a flat at the RHN, she showed many sensible responses that were consistent with her verbal report. This included politely declining to donate when a charity called unannounced. However she also ordered a take-away!

If Carol had shown awareness of the risks of eating, this would have been classified as an ‘unwise decision’ that she was entitled to make. During her interview however, Carol showed fluctuating awareness of her disabilities: at times she stated she was as able as ever, insisting she could jump, clap or perform any task requiring two arms or legs. She also had false memories of walking and eating, which were known not to have occurred - a phenomenon known as ‘confabulation’.

Taking all the evidence into account, we concluded that although Carol understood the relevant information, retained it and could communicate her decisions, her fluctuating awareness and confabulated memories meant she was unable to accurately use/weigh information and as such, she lacked capacity to make these decisions. She could however, actively participate in decision-making, and she was later discharged to suitable accommodation with a care package to manage the ongoing risks.

This case illustrates that questions of mental capacity can be complex when the cognitive consequences of brain injury are less common, less stable, and/or less amenable to formal assessment. However, with creative and thorough assessments, we are able to safeguard a person’s rights and best interests and ensure maximum participation in decision-making.

Dr Jessica Fish has worked in brain injury since 2003, initially as a researcher studying cognitive rehabilitation and later as a clinician. She previously worked with Sarah Crawford at the RHN and is now a clinical psychologist at the Oliver Zangwill Centre for Neuropsychological Rehabilitation, part of Cambridgeshire Community Services NHS Trust.

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Before qualifying as a clinical psychologist in 2002, Dr Sarah Crawford completed a PhD, examining measures for assessing real-life problem-solving after brain injury. Sarah specialises in complex neuro-rehabilitation and is currently consultant clinical neuropsychologist and professional lead for clinical psychology at the RHN.

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Carol was 36 when she suffered two strokes that left her unable to use her left arm or leg, or to swallow safely. She uses a wheelchair and obtains all hydration and nutrition from a PEG tube. While at the RHN, Carol expressed her intention to return to her previous accommodation on discharge and to eat a normal diet – both against clinical advice.

We assessed her mental capacity to make these decisions in a process comprising standardised cognitive testing and a set of assessments designed specifically for this case. We examined decision-making ability at a theoretical or verbal level using interviews and vignettes, and also at a behavioural level using a bespoke functional task directly relevant to the decisions in question.

The cognitive assessment showed that Carol’s intellectual, memory and executive abilities were within normal range. This meant she likely had capacity to make many decisions and could certainly participate in complex decision-making. In the verbal assessment of decision-making, Carol was able to learn the appropriate responses and to provide them consistently over several sessions.

In the functional task, which presented a variety of safety challenges within a flat at the RHN, she showed many sensible responses that were consistent with her verbal report. This included politely declining to donate when a charity called unannounced. However she also ordered a take-away!

If Carol had shown awareness of the risks of eating, this would have been classified as an ‘unwise decision’ that she was entitled to make. During her interview however, Carol showed fluctuating awareness of her disabilities: at times she stated she was as able as ever, insisting she could jump, clap or perform any task requiring two arms or legs. She also had false memories of walking and eating, which were known not to have occurred - a phenomenon known as ‘confabulation’.

Taking all the evidence into account, we concluded that although Carol understood the relevant information, retained it and could communicate her decisions, her fluctuating awareness and confabulated memories meant she was unable to accurately use/weigh information and as such, she lacked capacity to make these decisions. She could however, actively participate in decision-making, and she was later discharged to suitable accommodation with a care package to manage the ongoing risks.

This case illustrates that questions of mental capacity can be complex when the cognitive consequences of brain injury are less common, less stable, and/or less amenable to formal assessment. However, with creative and thorough assessments, we are able to safeguard a person’s rights and best interests and ensure maximum participation in decision-making.

Dr Jessica Fish has worked in brain injury since 2003, initially as a researcher studying cognitive rehabilitation and later as a clinician. She previously worked with Sarah Crawford at the RHN and is now a clinical psychologist at the Oliver Zangwill Centre for Neuropsychological Rehabilitation, part of Cambridgeshire Community Services NHS Trust.

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Consent in the context of the Care Act 2014 – a social worker’s perspective

Social worker Guy Soulsby is a mental health professional and best interests assessor, undertaking assessments under both the Mental Health Act 1983 (MHA) and the Mental Capacity Act 2005 (MCA). A specialist in dealing with issues of capacity, in this article he considers the impact of the Care Act 2014, which overhauled social care legislation, and discusses the implications for social workers where issues of capacity and consent exist.
As professionals, it is our duty to be familiar with the statutory framework within which we work. Whilst a recent survey presented by the British Association of Social Workers suggested that training for local authority social workers on the new Care Act (the Act) varies widely, a great deal of information exists thanks to journals, special interest groups and charities in addition to the Act itself and the statutory guidance. So what are the implications of the new Act for social workers who deal with issues of capacity and consent?

The first point is that though pre-existing social care law has now been replaced by the new Act, the MHA and MCA have not. What the Care Act actually says is that if there is a refusal of a needs assessment:

“the local authority … must carry out a needs assessment … if the adult lacks capacity to refuse the assessment and the authority is satisfied that carrying out the assessment would be in the adult’s best interests”.

The statutory guidance issued by the Department of Health in October 2014 states that:

“Where there is concern about a person’s capacity … then an assessment of capacity should be carried out under the Mental Capacity Act (MCA).”

Social workers must provide evidence to show:

i) how the person has understood – or not – the information provided

ii) how they have retained – or not – this information (which only needs to be for as long as it is necessary to make the decision)

iii) how they have used this information in making the decision (in this case not to have an assessment of care and support needs)

iv) how they have communicated their decision – and if they have problems communicating, specific support to help with this should be arranged

If the person lacks capacity there should be a best interests meeting to clarify if a needs assessment is necessary. Local authorities should have forms that are compliant with the MCA to help guide social workers through this process.

Service users as experts
The Care Act places great emphasis on service users being the experts with regard to their own needs and defining the type of services they will benefit from. They are to be active participants rather than passive recipients of assessment and planning for service provision.

It refers to assessment as a collaborative, transparent and understandable process and encourages supported self-assessment as long as the local authority is confident that the individual has the capacity to assess their own needs in accordance with the MCA. In cases where service users have the capacity to undertake a self-assessment but experience substantial difficulty in understanding and using relevant information, there is an option to involve a member of their support network or to provide an independent advocate to assist.

Even if the service user lacks the capacity to understand the need for an assessment they should still be involved as much as possible in the process. Refusing to be present may cause practical difficulties, but social workers are usually able to engage flexibly with service users as part of the on-going process of developing relationships and trust.

The test for ‘substantial difficulty’ is exactly the same as for assessing capacity and is set out from paragraph 7.11-7.14 of the Care Act statutory guidance. Local authorities must arrange an Independent Mental Capacity Advocate if there is no other appropriate individual to support the service user.

Engaging the individual
The main issues social workers have to face in respect of capacity in the context of the Care Act is deciding if people have capacity to refuse a needs assessment and their capacity to engage with it if an assessment is undertaken.

My personal experience is that determining capacity is straightforward in many cases, but there are exceptions. My biggest concern is how we engage the individual - not so much in the assessments themselves because there are usually lots of people that provide information, but in the support being offered. Fit and active young men with a brain injury who deny the extent of their problems, just wanting to get on with their lives, form a large part of the group we work with. But getting on with their lives may include drinking lots of alcohol and indulging in other ‘risky’ activities leading to greater harm.

There are legal frameworks to help us ‘manage’ this group, but the culture we operate in does not encourage long-term placements where individuals are deprived of their liberty except in situations where the risks are extreme. I am not sure the Care Act offers any potential additional solutions; my fear is that people who do not engage, who don’t face acute risks, and who can function in day-to-day terms will – in the current financial climate – quickly have support packages withdrawn.

Continued on page 16

Guy Soulsby is a qualified social worker and has worked almost exclusively with adults with brain injury in an NHS rehabilitation centre in Liverpool since 1995. He is on the Board of the Brain Injury Social Worker Group (BISWG), a membership organisation for social workers and other professionals who work in the field of brain injury.

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CASE STUDY

Instigating a needs assessment

Stephen sustained a brain injury in a fall and having completed six months in a specialist residential rehabilitation setting, the next step is an assessment of need for his continuing support. Before this takes place, his social worker speaks to Stephen’s treating clinician who confirms that Stephen lacks insight into the effects of his fall and that he also has difficulty processing lots of information quickly – both common symptoms of brain injury.

Therefore the social worker decides on an initial short meeting to determine Stephen’s needs. Her first step will be to evaluate if Stephen has difficulty understanding and therefore being involved in the assessment process. She is aware that lack of insight does not necessarily determine lack of capacity. Support, if necessary could come from a carer, family member, friend or Independent Mental Capacity Advocate.

The social worker notes that Stephen is able to retain information about who she is and why she is meeting with him. He is articulate about his plans for the future, including meeting up with friends and returning to work. A pre-assessment conversation with Stephen’s mother however, confirms that his friendship group has diminished significantly as his friends find it difficult to understand the changes in his behaviour and she doubts whether he will be able to return to full-time employment. Because Stephen lacks insight into his personal relationships and future plans, the social worker judges that he may also have trouble estimating his true care and support needs. At this point she decides that Stephen would have substantial difficulty in being fully involved in the rest of the assessment process and would benefit from assistance.

Stephen is adamant he wants to act and make decisions independently, though he is happy for his mother to inform the assessment process. The social worker decides that Stephen’s mother would not be an appropriate person to support his involvement in the needs assessment and talks to him about how an independent advocate could ensure his views, beliefs, wishes and aspirations are taken into account in the assessment. With his agreement, she arranges for an advocate with specialist brain injury training to support him. The advocate meets Stephen but also talks to his mother to get a true picture of Stephen’s current needs and wishes and to understand how he has changed since his injury. The social worker carries out the needs assessment with Stephen, supported by his advocate and, with Stephen’s approval, input from his mother.

Based on the Department of Health’s statutory guidance

This no-obligation, patient-centred advice service is delivered by expert professionals in an ethical way by a consortium of Brain Injury Group law firm members, with support from specialist financial and welfare advisers.

We can also provide free training for clinical staff dealing with brain injured patients and their carers on a range of legal and specialist subjects related to brain injury.

To find out more, please contact our Health Sector Manager, Alison Bartholomew, on 07879 882250 or by email at alison.bartholomew@braininjurygroup.co.uk

A FREE legal and welfare service for patients affected by brain injury, their carers and families that can be made available within a hospital or neuro-centre setting.
A power of attorney allows an individual (the donor) to authorise someone else (the attorney) to make decisions or act on their behalf if they are no longer able to, say through future loss of mental or physical capacity. Sarah Cash of Hugh James takes a look at two different types of powers of attorney and how they can be used.

Over the last few years, lasting powers of attorney (LPAs) have received increasing exposure in the press. There are two types: one for financial affairs and one for health and care, both of which must be registered at the Office of the Public Guardian before they can be used. Although typically associated with the elderly, an accident or illness could result in mental and physical incapacity at any time and LPAs can provide a valuable safety net should the worst happen.

Covering all bases
Financial decisions LPAs provide the attorney(s) with the authority to deal with the donor’s financial affairs (eg. bank accounts, property, bills, insurance, tax returns and benefits). As long as the LPA has been registered it can be used – with the donor’s authority – before mental capacity has been lost. The health and care LPA allows the attorney(s) to make decisions on the donor’s behalf regarding their health and wellbeing (eg. living arrangements, medical treatment, care and life sustaining treatment). The health and care LPA can only be used if the donor has lost mental capacity.

We recommend that everyone has an LPA, particularly property owners, farmers, holders of extensive assets, sole traders and partners in a business. Attorneys must be over 18 years old and a financial decisions attorney cannot be a bankrupt. The emphasis is on trust and if more than one attorney is appointed they can either act ‘jointly’ (do everything together) or ‘jointly and severally’ (together or individually).

Some people may still have an ‘old style’ enduring power of attorney (EPA), which remains valid if made prior to 1 October 2001. However, if you have an EPA, you may wish to check it still complies with your wishes: EPAs only related to property and finance and you might wish to consider putting a health and care LPA in place too.

Ordinary, or limited powers of attorney, are only valid whilst the donor still has mental capacity to make their own decisions regarding their finances, but can be useful if they want to give someone authority to deal with limited assets on their behalf eg. a bank account. They are also used in a range of legal situations, such as to allow someone to obtain a grant of representation in a deceased’s estate on behalf of the appointed executor.

A matter of trust
One of the biggest benefits of LPAs is the ability to choose someone you know and trust to act on your behalf if necessary. They offer different options regarding the number of attorneys and the number of ways they can act on your behalf – so you may wish to obtain professional advice if you are considering putting one in place. If mental capacity is lost without an LPA but authority is needed to make decisions, the only option is an application for a Deputyship Order, which can be costly and time-consuming. If correctly executed, powers of attorney can be extremely useful and should save further time and expense for the donor and their family.

Sarah Cash is a partner and Head of Tax, Trusts & Estates at Top 100 law firm Hugh James. Having qualified as a solicitor in 2002, Sarah has gained extensive experience in powers of attorney as well as wills, probate, trusts and tax.

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A dignified departure: rights and options for end of life care

Issues surrounding end of life care are fraught with emotion and rarely straightforward. Human rights solicitor Merry Varney discusses how end of life decisions for those with disabilities can be particularly open to misunderstanding and confusion.

It’s an emotive topic to tackle, but information about rights and options regarding end of life care can enable an individual to make important choices while they can so it doesn’t fall on others to make them. If you care for someone already unable to make these choices for themselves, knowing more about the issues may help you think about what might be in their best interests.

Unfortunately there remains considerable inequality across the health service, with patients with disabilities being more likely to die prematurely. Considering end of life care often involves considering quality of life, and this is an area where patients with disabilities are vulnerable to being misjudged and therefore a key area to ensure the patient’s wishes are known.

Advance Decisions: what do they cover?
Setting out your wishes in advance so that relatives and healthcare professionals know what you want if you lose mental capacity* is a crucial way of ensuring your rights are protected. It can also prevent your family feeling responsible for difficult decisions. As long as you have capacity, you can continue to make decisions and an Advance Decision only becomes relevant if you later lose capacity.

Where a patient does not have capacity to make medical treatment decisions, the doctor becomes the primary decision maker, being obliged to make a decision in their patient’s best interests.

* ‘Capacity’ in this context refers to the mental capacity to make the relevant health decision, including being able to retain and assess information given about different options.
+ Information on Advance Decisions and LPAs is available online and from organisations such as national charity, Compassion in Dying.
Family and carers should always be consulted, except in exceptional circumstances. If a valid Advance Decision has been made to refuse treatment, this should be respected.

Advance Decisions can cover any treatments you would not wish to receive, but cannot demand particular treatments. Advance Decisions do not cover a request for assisted dying, which remains unlawful in this country. The law also prevents anyone from refusing basic care, for example to maintain mouth care and personal hygiene. Advance Decisions are not the mechanism to nominate someone else to make decisions for you – this is a Lasting Power of Attorney (LPA) for health and welfare, which has some important differences to an Advance Decision.

The debate around DNRs
One of the most common decisions made in advance in relation to end of life care is the decision not to give a patient cardio-pulmonary resuscitation (CPR) if they suffer a cardiac or respiratory arrest.

Over recent years there have been multiple stories in the press about patients or their families discovering that a ‘do not resuscitate (DNR)’ decision has been made without them being informed or consulted. Last year the Court of Appeal unanimously ruled that these decisions must be discussed with patients and their families (unless the patient has asked for the family not to be informed or consulted) and that healthcare professionals cannot make the decision unilaterally.

There remains much confusion around DNR decisions and specifically the decision-making process. Patients or families do not need to consent to CPR being withheld, which many are completely unaware of. Whilst the law restricts the circumstances in which healthcare professionals can decide in advance not to provide a patient with CPR, patient consent is not a requirement.

There are three main circumstances where the law allows DNR decisions to be made by healthcare professionals:

1) Where a patient with capacity asks not to be resuscitated. This must be respected and a DNR order implemented to alert all healthcare professionals not to attempt resuscitation. This decision may be made at any time by a patient with capacity, and could be part of an Advance Decision made by a patient now without capacity.

2) Where a doctor considers that resuscitation is likely to be “futile” – i.e. in their medical opinion, CPR will not work.

3) Where a doctor considers, having had full consultation with the patient and/or their family and carers if the patient lacks capacity, that the burden of CPR outweighs the benefit to the patient – i.e. that CPR may restart the heart and breathing but the patient is likely to be left with a poor quality of life (a benefit v burden test).

All decisions should be made on an individual basis. However, there are real concerns that patients with disabilities and elderly patients may be subjected to ‘blanket’ decisions. An extreme example is the case of AWA, a man with Down’s Syndrome whose carers found an indefinite DNR decision had been made without any prior discussion with them or his family. The rationale for withholding resuscitation was stated by the doctor to be that AWA had “Downs Syndrome, unable to swallow (PEG fed), bed-bound, learning difficulties.”

If a patient or their family wants CPR to be attempted and the healthcare professionals have made a DNR decision, the patient should be offered a second opinion. If a dispute remains, legal advice is advisable, even though legal action in what could be the final days of a patient’s life will not be welcomed by anyone. Without any supporting healthcare professional however, a legal challenge to the withdrawal of CPR would be unlikely to succeed.

Thinking ahead
Disputes arise not only in relation to DNR decisions, but also in relation to other advance decisions by healthcare professionals not to offer particular medical treatment. Healthcare professionals may for example decide a patient should not be offered a bed in Intensive Care if their health declines, or that mechanical ventilation should not be offered. If everyone thought in advance about what they might want, discussed this with their doctor and made their wishes known, disputes would be considerably less likely – which is clearly better for everyone involved.

It is difficult to predict how the law will develop in this area given the strong voices on both sides of the debate over how best to provide end of life care. I feel that the most important issue is ensuring patients have the information they need to make informed choices and that we have a law protecting patient choice wherever possible. Where it is not possible, patients should be offered full explanations, which should help prevent feelings of discrimination or contemplating legal action during their final days.

Merry Varney is a solicitor in the human rights department of Leigh Day. She specialises in the protection of the rights of children, vulnerable adults and patients and has significant experience in healthcare and discrimination issues.

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Leigh Day
Depending on the extent of their injury, it’s likely that a brain-injured individual will be unable to manage all their own affairs and will need the support of others to act on their behalf. Some may already have an appropriate power of attorney in place, giving authority to a loved one to assist them in such circumstances (see page 17). However, the majority will not.

In this situation, the Court of Protection – which exists to safeguard the interests of people who don’t have the capacity to make decisions for themselves – can be called on to appoint a deputy to look after the affairs of the injured person, or ‘protected party’. The deputy, whether professional adviser or lay person such as a family member, is then responsible for the management of the affairs of the person lacking capacity. This is not a task to be taken lightly and Adrian Mundell of Ashton KCJ looks at the role of the deputy in more detail on page 7.

Sadly, Court of Protection involvement is very common when someone has sustained a brain injury and our membership includes a number of firms that have developed significant expertise in providing and managing deputyship services. We have therefore established the Brain Injury Group Court of Protection panel to support those who need help to manage their own affairs or those of a loved one or a client. Our panel is made up of experts that can assist with all Court of Protection matters whether they involve a claim or not. When it comes to a case involving a claim, this could include:

- assessing immediate needs including the authority to deal with interim payments and benefit payments
- advising on the purchase or adaptation of property
- providing long- and short-term investment advice
- providing ongoing management such as paying for care, completing tax returns and submitting annual reports to the Office of the Public Guardian

Members also have access to the UK’s leading provider of independent mental capacity assessments (TSF Consultants) and to an independent financial adviser that specialises in providing services to personal injury claimants (Nestor).

For further information about the panel and what you can expect of a professional deputy, visit our website at www.braininjurygroup.co.uk.

The Court of Protection only has jurisdiction in England and Wales. If someone living in Scotland does not have mental capacity, an application may be made to the Sheriff Court for the appointment of a Financial Guardian in relation to their property and financial affairs, and a Welfare Guardian to make decisions about such issues as medical treatment, care and accommodation.