

Parents of adults with autism: your rights

This document explains your rights in the UK as a parent of an adult with autism.

Once your son or daughter reaches the age of 18, by law, you are not entitled to make decisions on their behalf. We outline how this may affect you while your grown-up son or daughter continues to live with you at home and what happens when they leave home. We also tell you of some ways in which you can continue to best support your adult son or daughter with autism, under these circumstances.

Reaching adulthood

Once a young person reaches the age of 18, regardless of whether they have autism, legally, they are an adult. As a parent, you can no longer make decisions on their behalf. This is because by the age of 18, most young people become independent of their parents. They may still be very close to their parents and parents may continue to offer both financial and emotional support, however, it is considered inappropriate for parents to make decisions on behalf of their children by this time in their lives. In addition, our legal system does not allow a right of guardianship of an adult, except in very extreme circumstances and for a brief time.

In Scotland, the situation is different. A young person becomes an adult at the age of 16. In addition, the Adults with Incapacity (Scotland) Act offers a range of options to help an adult who lacks the capacity to make decisions and manage different areas of their life. It makes it possible for another adult to be given powers to make decisions on behalf of someone who cannot act for themselves.

Caring for an adult with autism at home

This situation is complicated when a young person with autism turns 18 and is unable to cope alone. Many young people with autism continue to live with their parents until well into adulthood.

If your adult son or daughter is still living at home, social workers and other service providers will generally keep you informed and involved about the services they provide. It is not in their interest to exclude you, especially as parents and the extended family still provide a huge amount of care to adults with autism and are therefore valuable partners in the provision of care.

What happens when an adult with autism leaves home?

When a person with autism leaves home, your rights are not so clear. The way in which care services are provided to adults with autism is governed by the NHS and Community Care Act 1990, which says: "The individual service user and normally, with his or her agreement, any carers should be involved throughout the assessment and care management process. They should feel that the process is aimed at meeting their wishes." (Section 3.16 of Community care in the next decade and beyond: policy guidance, published by the Department of Health)

This means that care managers should consult parents when carrying out an initial assessment and in recommending a placement, but after that, your rights as parents are not clear. However, you can do a number of things to make it easier for you to remain involved with your son's or daughter's care. Many placements will have a policy on how they involve a client's family. Ask for this policy before choosing a placement as this may give you some idea of your rights as a parent.

A person with autism can be socially isolated so you can also help your adult son or daughter by trying to maintain as many existing links as possible with friends and family. This will help them make the transition to living away from home.

If, at any time, you are not happy with the services provided and feel that they are not suited to your child's needs, you can complain either through the complaints procedure at your child's placement or through the local authority, if they are funding the care. If your son or daughter is receiving residential care from the NHS for example, if a young person with autism has additional mental health needs you still have the right to complain. You can complain about residential care in the NHS with the help of the Independent Complaints Advocacy Service (ICAS). Your local Patient Advice and Liaison Service (PALS) will have ICAS contact details.

Citizen advocates

Parents are often their children's main advocates well into adult life. However, when you feel you are not being listened to or if you are concerned you will not always be around to represent your child, you have the option of appointing an independent citizens advocate. Citizens advocates are volunteers who befriend and get to know individuals, often those with acute needs, and help them to get their voice heard by official organisations such as health, social, education or care services.

A number of citizen advocacy schemes operate around the UK.

Lasting Power of Attorney

Here is some basic information on Lasting Powers of Attorney (LPA) and how someone can be appointed to make decisions on another person's behalf.

If you feel you need more detailed advice you may want to contact a legal professional. Details of how to find one are in the 'Useful contacts' section. You can also get further information on setting up an LPA from the Office of Public Guardian. Please note that this information applies to law in England and Wales only, although a brief note on the position in Scotland is also given.

What are Lasting Powers of Attorney?

A Lasting Power of Attorney (LPA) is a document which gives authority to a named individual or individuals to make decisions on another person's behalf. The person who is given the authority is known as an attorney. The person an attorney makes decisions for is known as the donor. These terms will be used in this information sheet.

There are two types of LPAs:

1. A Property and Affairs LPA. This gives attorneys power to make decisions about a donor's financial matters, for example operating a bank account, making investment decisions, signing tax returns and buying a house for the donor to live in.
 2. A Personal Welfare LPA. This gives attorneys power to make decisions about a donor's health and social care, for example to decide where the donor lives, and the provision of care and medical treatment.
- The donor can create one or both types of LPA and if both, can do it at the same time or at different times.

The powers given in either form of LPA cannot be exercised until it has been registered (unlike the former enduring power of attorney). It is, though, possible to grant powers relating to property and affairs (but not personal welfare) that are effective while the donor still has capacity (please see the question below for a definition of mental capacity).

A Property and Affairs LPA cannot be used to make decisions on matters of personal welfare. A Personal Welfare LPA cannot be used to make decisions on financial matters.

If a donor wants someone to make decisions about both personal affairs and financial affairs they should create both types of LPA. The donor can appoint the same person as an attorney on the two LPAs, or can choose a different one for each.

Who decides that an LPA is needed?

The donor, and only the donor. However the donor can only grant the LPA if s/he has the mental capacity to make this decision. Having mental capacity means that a person has the ability to make decisions for themselves. Mental capacity is defined in the *Mental Capacity Act 2005* (the Act), which assumes a person has mental capacity unless it is proven otherwise. The Act goes to great lengths to define a person who has or who lacks capacity.

People are assumed to have capacity if they:

- understand information relevant to a decision
- remember that information long enough to make a decision
- use or weigh up the information available when making the decision or communicate their decision in any way which can be recognised (eg using sign language or any other understandable way).

Further key points are:

- a person's lack of capacity may be only partial or temporary
- a person may lack capacity in respect of one matter but not others
- the inability to make a decision must be the result of an impairment or disturbance of the functioning of the brain
- when determining capacity a decision should not be made merely on the basis of a person's age, appearance or unjustified assumptions about capacity based on the person's condition or behaviour.

Any person over the age of 18 who has mental capacity can be an attorney. It is important that a donor chooses an attorney s/he knows well. It is also important that attorneys feel able to take on such a responsibility and think they will be able to make the right decisions on the donor's behalf and in the donor's best interests.

It is possible to appoint more than one attorney on an LPA. If a donor decides s/he wants more than one attorney it is necessary to decide whether the attorney's power should be joint or joint and several. If joint is chosen, this means that all the attorneys have to agree and act together on all decisions. Sometimes this can cause problems as there may be a delay in making important decisions while waiting for all attorneys to agree. If the power is joint and several this means that the attorneys can either act together, or else each attorney can make decisions independently of the other attorneys. While this may speed up decision-making, the donor may not feel happy letting one person make all of the decisions.

It is possible to specify that some decisions should be made by all attorneys acting together (jointly) and other decisions may be made independently (severally). It could, for example, be decided that the most important decisions affecting the donor's life and/or finances should only be made jointly.

An attorney's power can be limited by expressly excluding them from making certain decisions. For example it can state in a Property and Affairs LPA that the attorney(s) cannot sell a donor's house or certain possessions.

How is an LPA created?

The form produced by the Office of the Public Guardian must be used to give an LPA to someone. Details of how to obtain the form can be found in the 'Useful contacts' section.

The form must be signed by the donor and by the attorney(s) and when sent in for registration must be accompanied by a certificate by someone who can confirm the donor understood the purpose and scope of the LPA, that there was no fraud or undue pressure involved, and that there is nothing that would prevent the LPA being registered. People who can provide this certificate (known as an authorised person) are:

- a person who has known the donor personally for at least two years or
- a professional who has the ability to judge if someone has mental capacity. This could be a doctor, social worker or lawyer.

People who cannot sign the certificate include:

- the attorney(s) named in the LPA
- family members of the donor
- an employee of the care home where a donor lives.

People dealing with an attorney will want to see the LPA to ensure that the attorney has the power to act as proposed.

When can an LPA be used?

An LPA cannot be used until it has been registered with the Office of Public Guardian. Either the donor or the attorney(s) can register it. It is possible to indicate on the LPA if someone specific is to be notified when the LPA is registered. The power does not have to be registered as soon as it is signed - a donor may only want it registered once s/he has lost mental capacity. It may be that s/he will never lose mental capacity, in which case the registration fee will never have to be paid. The danger though is that when submitted for registration there may be a problem which cannot then be rectified because the donor no longer has mental capacity to sign a new form.

Examples of possible scenarios:

- **Helen** has high-functioning autism. She lives in a residential home. Recently she has had some difficulties managing her finances. She is also concerned she may not be able to make decisions regarding her welfare in the future. Her sister, Sally, and her aunt, Joan, want to help her and agree to be named as attorneys on a Property and Affairs LPA. They all sign the document and register it straight away so they are able to manage Helen's finances immediately. They are also named as attorneys on a separate Personal Welfare LPA. This is signed but is not registered straight away. It will only be registered if Helen loses the mental capacity to make welfare decisions herself. In the meantime she gives it to Sally for safekeeping. Helen's GP acts as the Authorised Person.

- **James** has Asperger syndrome. He lives with his parents but wants more independence and is looking forward to moving into supported living in a year's time. However, he is not confident with money matters and thinks that he needs someone to oversee them for him. His older brother, Tom, is happy to help and agrees to take on the responsibility of holding a LPA Property and Affairs. They sign the document, but James does not register it until one month before he moves into his supported living tenancy. In the meantime, before registration, the LPA document is kept safely with the family solicitor, who also acts as the Authorised Person.

The donor, attorneys or the people notified can object to the registration if they feel it is not necessary. If no one objects, the Office of Public Guardian will register the power and notify the donor and attorneys of this. The Office of Public Guardian keeps a register of LPAs.

An LPA can be revoked at any time whilst the donor has mental capacity using a Deed of Revocation. It is important for anyone wishing to use a Deed of Revocation to get legal advice.

What decisions can attorneys make?

Once an LPA is registered, the decisions an attorney can make on behalf of a donor will depend on what type of LPA it is and if any restrictions have been put on the attorneys powers by the donor in the LPA.

Property and Affairs LPA

Attorneys can use all the powers granted by a Property and Affairs LPA whether or not a donor has mental capacity once the LPA is registered. Under this LPA attorneys have the power to decide how to spend a donor's money and how to manage their property and affairs. In certain circumstances they can make gifts to people and charities on behalf of the donor.

Personal Welfare LPA

A donor must have lost mental capacity before an attorney can act under a Personal Welfare LPA. The decision about loss of mental capacity can be made by a doctor. This LPA allows attorneys to make decisions about a donor's social and health care. Unless excluded, this includes consenting to health care treatment. A donor can also give express power to allow attorneys to refuse health treatment on their behalf. However, if the person has already made what are called advance conditions about medical treatment, they could take precedence over an LPA.

What about Enduring Powers of Attorney?

An Enduring Power of Attorney (EPA) is a type of power of attorney that was used before LPAs were created. New EPAs can no longer be created. However, EPAs created before 1 October 2007 are still valid and can still be registered and used. EPAs do not give attorneys power to make decisions about welfare or health care issues, only financial issues. If you have previously created an EPA and think someone may need to make welfare or health decisions for you in the future, you should consider creating a Personal Welfare LPA.

What if a person cannot create an LPA?

The NAS often gets calls from parents who wish to ensure their adult child gets the right help. However, they often feel that professionals from social services or the medical profession will not listen to them as

their child is an adult. They therefore want to be given a power of attorney. However, if their child does not have the mental capacity required to create an LPA, then that option is not available.

The Mental Capacity Act 2005 (the Act) ensures that everyone aged over 16 should be able to make their own decisions unless and until it can be shown they lack the mental capacity to do so. It emphasises the importance of using a variety of means of communication to help those who find communication hard to make their own decisions. For people with autism this may mean using alternative means of communication. This may be visual support or signing.

Other individuals may need an advocate. An advocate can communicate someone's opinions on their behalf and help them make decisions. There are a number of organisations which provide advocates for people. To find details of a local advocacy organisation please refer to the 'Useful contacts' section below. The Act also allows people to make decisions on behalf of those who lack mental capacity. Some of these decisions can be made informally, without the need for an LPA, provided they can demonstrate that they are acting in the individual's best interests - this might include helping the individual to wash, dress, eat, attend to their personal hygiene, taking them to the doctor or dentist or helping them with other aspects of day-to-day living.

However, for other decisions on property or financial affairs or ongoing welfare decisions where the option of a LPA is not available, an application needs to be made to the Court of Protection. The Court of Protection can give someone power to make a decision on something specific or appoint deputies to make decisions on an ongoing basis. The Court can also resolve disagreements between carers and social workers on how a person should be best cared for. Further information on making an application to the Court of Protection can be obtained from the Office of Public Guardian.

The position of children

Under the Act, a child is a person aged under 16, whilst a 16- and 17-year-old is referred to as a young person. This is different from the general law, where a child is a person under the age of 18.

The Act does not generally apply to a child under the age of 16 and the LPA is therefore not relevant; however the Court of Protection can make decisions about a child's property or finances (or appoint a deputy to do so) if the child lacks capacity and is likely to lack capacity at the age of 18.

Most of the Act applies to young people aged 16 and 17, but again the LPA is not available as only people aged 18 and over can make a LPA. Also only people aged 18 and over can make an advance decision to refuse medical treatment.

The position in Scotland

The *Adults with Incapacity (Scotland) Act 2000* provides different ways for people to manage the affairs of those who are unable to act for themselves. It is possible to have two powers of attorney, one for financial matters (a continuing power of attorney) and one for personal welfare (a welfare power of attorney). A different attorney can be used for each.

Again a person can only grant a power of attorney if capable of understanding what he or she is doing. No one, not even close relatives, can arrange a power of attorney for someone else, so it must be done while the donor is able to express their own wishes. If a potential donor or attorney would like more information on the role of the attorney, the Scottish Executive has published a code of practice. This publication, *Adults with Incapacity (Scotland) Act 2000: Code of Practice for Continuing and Welfare Attorneys, March 2011* can be found by using the search facility on the following website: www.scotland.gov.uk

All information above can be found at the National Autism Society's web-site!