

# Physical, Emotional and Mental Health



This section is about your relative's right to be healthy. Having a physical health condition significantly increases the risk of developing an emotional and mental health condition and vice versa. Nearly one in three people with a long-term physical health condition also have an emotional and mental health condition. If your relative is in pain (either chronic or acute) and this is not addressed, it can impact on mood and could lead to depression or an increase in behaviour described as challenging.

## Useful terms:

Chronic or persistent pain is **pain that carries on for longer than 12 weeks despite medication or treatment.**

Acute pain **begins suddenly and is usually sharp.** It serves as a warning of disease or a threat to the body. Examples of acute pain include a broken bone or cut.

## The Learning from the Lives and Deaths of People with a Learning Disability and Autistic People (LeDeR) Programme

In 2017 the LeDeR programme was established. It aims to:

- Improve care
- Reduce health inequalities
- Prevent the early deaths

of people with a learning disability, autism or both

The LeDeR publishes an annual report and every year it confirms that people with a learning disability, autism or both face many health inequalities, often resulting in worse health than the general population: Here is some of the information from this year's reports:

- 62 was the average age of death for people with a learning disability, autism or both. In the general population it was 82.7
- 49% of deaths were classified as 'avoidable' for people with a learning disability, autism or both. This compares to 22% for the general population

## Family Carer Advocacy Resource

- COVID-19 was the leading cause of death for people with a learning disability, autism or both in 2021
- 8% of avoidable deaths were linked to cancer, 14% to hypertension, 17% to diabetes and 17% to respiratory conditions

**Look at the full summary factsheet or read the most recent report here:**

[Click here to look at the full summary factsheet](#)



[Click here to read the most recent report](#)



Article 2 of the Human Rights Act protects your right to life. This right places an obligation on public authorities to provide life-saving or life-prolonging medical treatment. If a health and social care organisation or professional knowingly withhold care and support and/or treatment this can be classed in law as ill treatment/wilful neglect.

## Emotional and Mental Health

**Read this case law example:**

In R v Sheppard [1981] A.C. 394 the Court held that the primary meaning of wilful is “deliberate”. Therefore, for example, someone who knows that the person in their care needs medical assistance and deliberately, that is by conscious decision, refrains from calling a doctor would be guilty of wilful neglect. Equally, a person who fails to provide medical care because he does not care whether it is needed or not is reckless and is also guilty.

Source: [The CPS](#)

People with learning disabilities, autism or both are just as likely to experience poor emotional and/or mental health, with some research indicating there is an increased risk. Despite this, mental health conditions in people with a learning disability, autism or both often go undiagnosed.

Mental health includes emotional, psychological, and social well-being. It affects how people:

- think
- feel
- act and behave
- handle stress
- relate to others
- make choices

### Key Message:

Learning disability and autism are not mental health conditions. The Mental Health Act reforms include removing the terms ‘learning disability and autism’ from the list of conditions included under the definition of ‘mental health disorders’. This means that it will be harder to detain people with a learning disability, autism or both under the Mental Health Act unless there is a clear mental health diagnosis, e.g. depression, psychosis. In addition, all current guidance emphasises the need for any interventions for a mental health condition to be available as early as possible and in the community because it is acknowledged that the outcomes for people with a learning disability, autism or both are rarely positive following admission to a mental health service.

**Read this fact sheet ‘What’s the difference between a learning disability and a mental health problem?’ from Mencap:**



[Click here to read the fact sheet](#)

## Family Carer Advocacy Resource

There are a number of reasons why your relative has an increased risk of developing either a physical or emotional and mental health condition or both. Here are some examples:

	Physical Health Conditions	Emotional and Mental Health
<b>Biological factors</b>		
Some syndromes and diagnosis are associated with an increased risk of developing certain physical and/or emotional and mental health conditions	Down's Syndrome and heart or lung problems	Fragile X Syndrome and anxiety  Prader Willi and obsessive-compulsive disorder  Autism and eating disorder  Response to sensory environment, e.g. being overwhelmed or finding certain stimuli such as noise, bright lights stressful
Side effects of medication	Psychotropic medication can cause: <ul style="list-style-type: none"> <li>● constipation</li> <li>● weight gain leading to diabetes</li> </ul>	Psychotropic medication can cause: <ul style="list-style-type: none"> <li>● sleep problems (sedation or wakefulness)</li> <li>● overly controlled emotions both positive and negative e.g. inability to cry</li> </ul>
Genetics	Increased risk of health conditions such as cancer e.g. being a carrier of the BRCA (breast cancer) or HNPCC (bowel cancer) gene	Increased risk due to genetics, e.g. a family history of depression.  <a href="#">Click here to read more from Rethink Mental Illness</a>
<b>Social and economic factors</b>		
Poor or inadequate housing	Overcrowding increasing risk of illnesses such as sickness and diarrhoea, flu, Covid  Poorly maintained housing leading to conditions such as damp increases the risk of some illnesses, e.g. respiratory	No choice about living companions which means your relative may find themselves in a position where they are living with people they don't get on with, are frightened off, have different support needs which can contribute to anxiety and/or depression
Location of housing	Poor transport links making access to facilities such as leisure centre, swimming pool difficult leading to sedentary lifestyle	Living in an unsafe area  Lack of acceptance from neighbours/community including prejudice/discrimination/hate crime which can contribute to anxiety and/or depression

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<p>Low income, poverty</p>	<p>Food choices due to limited income contributing to weight management (under and over)</p> <p>Not enough physical activity leading to decreased mobility, weight gain because of limited income to cover for example entry fees to swimming or gym sessions</p>	<p>Lack of access to meaningful activities leading to poor quality of life</p>
<p>Negative life events</p>		<p>Abuse and/or trauma (including undetected)</p> <p>Poor transition planning from children to adult services</p> <p>Grief and loss:</p> <ul style="list-style-type: none"> <li>● death of loved ones</li> <li>● placement breakdowns</li> <li>● moving services</li> <li>● high turnover of support staff</li> <li>● loss of important relationships because of placements far from home</li> </ul>
<p>Use of restrictive interventions</p>	<p>Injuries due to physical intervention</p> <p>Blanket restrictions/risk aversion support prevent participation in physical activities</p>	<p>Trauma:</p> <ul style="list-style-type: none"> <li>● fear of when the next restraint/ seclusion will happen</li> <li>● psychological trauma such as name calling, being belittled, made to feel worthless</li> <li>● secondary trauma, e.g. observing a peer being restrained</li> <li>● poor quality of life due to blanket restrictions</li> </ul>
<p>Attitude of others</p>	<p>Healthcare professionals making assumptions about physical health needs e.g. not recognising, or not considering it important</p>	<p>Discrimination</p> <p>Disability hate crime</p> <p>Being treated differently</p>
		<p>Discouraged from using person-centred coping strategies, e.g. repetitive activities such as rocking, listening to the same song</p>

## Family Carer Advocacy Resource

Care and support		
Inadequate level of care and support	<p>Prevents participation in meaningful activities including physical activity</p> <p>Limited person centred support and therefore choice and control</p>	Lack of choice and control results in negative emotions like hopelessness
Quality of staff, e.g. training	<p>Direct support staff do not have the knowledge or skills to support your relative to develop:</p> <ul style="list-style-type: none"> <li>● good daily living routines, e.g. oral hygiene, cutting finger/toe nails. Unattended this can lead to infection.</li> <li>● a healthy lifestyle e.g. diet and exercise</li> </ul> <p>No attention given to the importance of regular screening for breast cancer, testicular cancer</p>	<p>Emotional and mental health not prioritised or considered important by staff</p> <p>Staff not skilled in monitoring and detecting early warning signs of deteriorating emotional/mental health needs</p> <p>Staff may not be aware of their own emotional and mental health needs and how this may impact on the way they carry out their role</p>
	Physical symptoms of stress e.g. high blood pressure	Masking. This term describes how people with a learning disability, autism or both learn (consciously or unconsciously) to try and fit in. It can be exhausting and contribute to increased emotional overload, including stress and behaviour described as challenging
		<p>Poor self-esteem and confidence due to:</p> <ul style="list-style-type: none"> <li>● lack of opportunities for paid or voluntary work</li> <li>● support staff may not understand the importance of promoting independence, adopting a 'do for' or 'do too' model of care and support instead of supporting your relative to develop the skills to do things for themselves, e.g. cooking a meal of their choice</li> </ul>

		No attention given to teaching coping strategies or no acknowledgement of the importance of ensuring access to activities that your relative uses to manage their mood, e.g. going for a walk, drive.
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## Reasons why your relative's physical, emotional and mental health may go unnoticed or untreated

- Diagnostic overshadowing. This is defined by the General Medical Council (GMC) as "symptoms of physical ill health that are mistakenly attributed to either a mental health/behavioural problem or as being inherent in the person's learning disabilities". This means that health and social care professionals assume that any changes in your relative's behaviour are related to their learning disability, autism or both and fail to consider that their symptoms may be because of a physical, emotional or mental health condition or a combination of both.
- Communication difficulties:
  - Your relative may not have the skills or have been taught the necessary vocabulary to tell somebody when they are unwell
  - If nobody is listening or checking in with your relative to ask how they are, their health needs may go unnoticed.

[This resource provides ideas about talking about feelings](#)



- Your relative may not know what is normal and what needs medical advice or intervention. For example, if your relative does not know it is important for them to go to the toilet regularly, they may become constipated. If your relative

is female and their menstruation cycle stops, they may not be aware that this could be an indication of the menopause

- Making assumptions, for example your relative starts to sleep more and it is judged as laziness, instead of considering other possible reasons such as pain or depression
- Mental health conditions may develop and present in different ways compared to people without a learning disability, autism or both. For example, if your relative has good communication skills, they may be able to say that they are hearing voices, having persistent thoughts, or thinking about harming themselves but if your relative has complex communication difficulties they may not have the vocabulary or skills to communicate this, except through their behaviour
- Difficulty in diagnosing using standard tools e.g. questionnaires which either require your relative to self-report or rely on other people to complete on their behalf
- Healthcare professionals lack the training or skills necessary to address and treat physical, emotional and mental health conditions, e.g. no knowledge of reasonable adjustments, medical conditions associated with specific syndromes, reluctance to treat people with a learning disability, autism or both if they are considered to have behaviour described as challenging
- Limited focus on early intervention including standard health screening such as mammogram, smear test, colonoscopy (bowel cancer screening)

### Knowing when something is wrong

As a family carer you know your relative and what is normal for them when they are well (physical, emotional and mental health) and the signs to look out for when they are unwell or in pain. Use standard tools to regularly assess your relative's health and record the findings so that any changes are noticed and addressed promptly.

#### Physical health

**Disability Distress Assessment Tool:**

[Click here for the tool](#)



**Read this resource from Public Health England 'How social care staff can recognise and manage pain in people with learning disabilities':**

[Click here to read the resource](#)



#### Emotional and mental health

Guidance from NICE (the National Institute of Care Excellence) recommends that those caring and supporting people with a learning disability, autism or both should consider a mental health condition if the following changes in behaviour are noted:

- loss of skills or needing more prompting to use skills
- social withdrawal
- irritability
- avoidance
- agitation
- loss of interest in activities they usually enjoy

[Read the full guidance here](#)



Other changes to note include:

- Sleeping too much or too little
- Change in appetite (increase or decrease)
- Having low or no energy
- Increase or decrease in emotions, including mood swings
- Unexplained aches and pains
- "Self-medicating" through substance misuse (drugs and alcohol)
- Refusing to participate in activities they usually enjoy
- Increase in behaviour described as challenging, particularly self-injurious behaviour.

**In this video clip family carers explain how their relative displays behaviour described as challenging to express pain. There is also a fact sheet you can read:**



[Click here to watch the video and read the fact sheet](#)

**You can use the Glasgow Depression Scale to monitor mood:**



[Click here to read the Glasgow Depression Scale](#)

**Use this wellbeing journal to start a conversation with your relative about emotional and mental health:**



[Click here to access the wellbeing journal](#)

**NICE guidelines suggest a mental health care plan:**



[Click here to read the section on Assessment \(para 1.8\)](#)

## Family Carer Advocacy Resource

**Use a hospital passport to record information about your relative's health. There are many templates available, and it doesn't matter which one you use as long as the information is recorded, kept up to date and people know where to find it:**

[Click here for a template from the National Autistic Society](#)



**Family carer Kate tells us how her daughter Laura's hospital passport provides vital information whenever she needs any type of medical intervention in hospital:**

[Click here to read more](#)



### Supporting your relative to stay healthy

- Check with your GP whether your relative is on the learning disability register
- Being on the learning disability register should ensure that your relative receives an annual health check. This is an entitlement for people with learning disabilities aged 14 and over. Since April 2008 there has been extra money for GPs who do these. Even if your relative sees their GP regularly an annual health check is still a good idea as it will check things that are not looked at during a regular appointment. The health check typically includes:
  - a physical check-up, including weight, heart rate and blood pressure
  - a urine sample
  - a blood test
  - a chat about lifestyle e.g. level of exercise, weight management and any support required to stay healthy
  - discussion about emotional and mental health including any changes in behaviour, e.g. being sad and crying more, lack of motivation to participate in favourite activities, getting angry easily

- questions about health care needs that are more common if you have a learning disability, autism or both e.g. epilepsy, constipation
- a review of any prescribed medication, including psychotropic medication



[Click here to access the medication pathway](#)

- check to see if vaccinations are up to date e.g. Covid, flu
- follow up on any other health appointments

**Everyone who has an annual health check-up should be offered a health action plan. This could include referrals to other health care professionals such as a dietician because of concerns about your relative being over/under weight. Here are some examples of health action plan templates:**



[Click here to go to the learning disability page on the Surrey County Council Website](#)



[Click here for a template from the Coventry and Warwickshire Clinical Commissioning Group](#)

- Ask your GP if they can add information to your relative's Summary Care Record (SCR). A SCR is an electronic record of important patient information (e.g. prescribed medications, allergies, communication needs, any reasonable adjustments required) created from GP medical records which can be shared with authorised health care professionals.



[Read this easy read photo story about adding additional information to your summary care record](#)



## Family Carer Advocacy Resource

- Find out whether the reasonable adjustment flag is operating in your local authority

[Click here to find out more about the reasonable adjustment flag](#)



[Click here to watch a video](#)



- Ask for a referral to a community learning disability nurse and/or a learning disability liaison nurse

[Click here to read more about learning disability nurses](#)



- Seek professional support for any behaviours described as challenging which could be because of an unmet health need

[Click here to read more from the Challenging Behaviour Foundation](#)



- Make sure you are aware of potential side-effects of any medications your relative is prescribed (including psychotropic), monitor carefully and request regular reviews.

[Click here to read more information on the use of medication](#)



- Input from your local Community Team Learning Disability can support your relative's physical, emotional and mental health. The referral process varies across local authorities, but most allow self-referrals. The CTLD team typically includes the following health care professionals:

- Psychology

- Psychiatry
- Occupational therapy
- Physiotherapy
- Speech and language therapy
- Behavioural support
- Specialist community nursing

and they should adopt a multi-disciplinary approach (work in partnership)

- If your relative is detained (sectioned) under the Mental Health Act, on admission your relative, or you on their behalf, should request a physical health check. This will ensure that if there are any underlying physical health conditions which are contributing to a deterioration in emotional and mental health and/or increase in behaviour described as challenging this can be addressed promptly. If during their detention, your relative develops any physical health conditions, then it is the responsibility of the service to ensure that they receive prompt and appropriate treatment

### Oral health

Ensuring your relative is fit and healthy includes their oral health. A Public Health England report in 2019 looking at oral health inequalities said approximately one in three adults with a learning disability, autism or both have:

- unhealthy teeth
- higher rates of untreated decay
- a greater number of extractions
- a higher prevalence of complete tooth loss

than the general population.



[Read this factsheet on accessing dental care](#)



[Visit this website for advice and guidance for autistic people and their family carers](#)

### Emotional and mental health

One of the best interventions to support your relative's emotional and mental health is to ensure they have a good quality of life and there is legislation in place which acknowledges this:

- Care Act and the principles of wellbeing
- Human Rights Act, e.g. article 3 Freedom from torture and inhuman or degrading treatment
- [CQC's inspection process](#) and good practice guidance

**This report provides a service model for commissioners of health and social care services. It includes a visual on page 12 illustrating the nine elements which contribute to a good quality of life:**



[Read the full report here](#)

### Treatment and therapies available to support your relative's emotional and mental health

Any treatment/therapy your relative receives should be person-centred and include any required reasonable adjustments according to the Equality Act.

[Read this good practice guide here](#)



#### Key message:

Most treatment and therapies can and should take place in the community. The Mental Health Act states: "Where it is possible to treat your relative safely and lawfully without detaining them, this is what should happen." Your relative (if they have capacity) or you (on their behalf as their family carer) should always ask "What are the benefits of being admitted to a mental health service. What care and/or treatment is being offered that can't take place in the community".

### Social Prescribing

Ask your GP about social prescribing. This means 'prescribing' a social/community activity instead of just a clinical solution. It is an early intervention treatment to address social and emotional needs such as loneliness/isolation and prevent a deterioration in emotional and mental health. Your relative's GP refers your relative to a Social Prescribing Advisor who develops a personalised action plan to improve your relative's health and well-being. This may involve support to access local opportunities and activities. Social prescribing can also help with physical health conditions, e.g. membership of a gym will help with weight management.



[Read this article for more information on social prescribing](#)

"... most of them have histories of past adverse life events and significant trauma but there is little evidence of any trauma informed care and plenty of evidence of people being re-traumatised during their hospital stay..."

Source: Baroness Hollins in her letter dated 18th December 2020 to The RT Hon Matt Hancock MP, the then Secretary of State for Health and Social Care.

### Trauma Informed Care

Ensure that Trauma Informed Care (TIC) is part of your relative's care, support and/or treatment. Trauma results from exposure to an incident or series of events that is emotionally disturbing or life-threatening. Examples of events that may be traumatic include use of restrictive interventions, placement breakdowns, abuse (physical and psychological), continuously being exposed to an environment which contributes to sensory overload.

## Family Carer Advocacy Resource

Instead of asking the question “What’s wrong with you”, trauma informed care asks, “What happened to you”.

[Follow this link for further information](#)



### **‘4 Rs’ for trauma informed care**

- 1.** ‘Realisation’ about trauma and how it can affect people/groups. There are situations where people experience trauma as a group, for example in some of the highly publicised cases of abuse such as Winterbourne View. Everybody within the service was affected, regardless of whether they were being directly abused or not.
- 2.** ‘Recognise’ the signs. Being easily startled or frightened, behaviour described as challenging, feelings of guilt and shame.
- 3.** ‘Respond’ to the trauma. Provide safe, nurturing, empathetic care and support.
- 4.** ‘Resist’ retraumatisation.

**Watch this animation from CQC which includes how the use of restrictive interventions reminded somebody of the abuse they had experienced:**

[Click here to watch the animation](#)



**This infographic describes the effects of trauma, how retraumatisation happens and what can help:**

[Click here for the infographic](#)



**Read this factsheet Understanding the effect of trauma on health:**



[Click here to read the factsheet](#)

**This trauma informed toolkit is for family carers:**



[Click here for the toolkit](#)

**Read this blog about Ben’s experience following abuse at Winterbourne View and a trauma informed care approach:**



[Click here to read the blog](#)

**Respond is a national charity providing therapy and specialist support services to people with learning disabilities, autism or both who have experienced abuse, violence and trauma:**



[Click here to go to the Respond website](#)

**Read the Challenging Behaviour Foundation’s report “Broken” about how trauma impacts on family carers and their relatives:**



[Click here to read the report](#)

## Family Carer Advocacy Resource

Eye movement desensitization and reprocessing (EMDR) is recommended by NICE as the first treatment for people with symptoms of post-traumatic stress disorder and there is some evidence that people with a learning disability, autism or both can benefit from this therapy. The approach is based on recognising that the thoughts, feelings and memories associated with a traumatic event can get stuck and make it hard to move on. EMDR aims to help the brain to process distressing memories and reduce their influence.

**Complementary and alternative therapies, e.g. massage, mindfulness, weighted blankets:**

[Click here to read more](#)



**Music or dance therapy. These therapies can be useful if your relative finds verbal communication difficult:**

[Click here for more information about music therapy](#)



[Click here for more information about dance therapy](#)



**Skill teaching, e.g. how to recognise stress and being aware of strategies which help such as participation in a particular activity, e.g. listening to music, walking, building resilience:**

[Click here to read a blog about building resilience](#)



**Increase supportive networks and reduce social networks:**

[Watch Zack's story here filmed as part of Mental Health Awareness Week 2001](#)



[Click here to read an article from Learning Disability Today](#)



**Talking therapies such as Cognitive Behaviour Therapy and Dialectical Behaviour Therapy**



[Read this article from Learning Disability Today about Cognitive Behaviour Therapy](#)



[Click here to read a blog about Dialectical Behaviour Therapy](#)

**Key message:**

Medication should not be the first and only treatment offered. If medication is suggested then it should be alongside a clear diagnosis, with a commitment to monitoring its impact and changing any other factors which could be contributing to the change in your relative's emotional and mental health, e.g. addressing a physical health need.



[Follow this link for more information about medication prescribing and good practice](#)

## Your relative's rights

The Equality Act 2010 says that service providers, (e.g. hospitals, GP surgeries, dentists) must take reasonable steps to remove barriers which stop people with a learning disability, autism or both from having access to the same health care services as everyone else.

This is referred to as reasonable adjustments and they are a legal requirement. People are individuals so reasonable adjustments need to be person-centred.



[Click here to see a reasonable adjustments wheel](#)

## Family Carer Advocacy Resource

### Anticipatory reasonable adjustments

- wheelchair access
- lifts
- information in a range of formats, e.g. easy read

### Appointments

- timing, e.g. first/last appointment of the day
- longer appointment
- priority appointments

### Sensory needs

- provide a private room (to wait or on a ward)
- plan a quieter route in and out of buildings
- flexibility about hospital gowns, ID wrist bands

### Communication

- provide information in a person-centred format, e.g. easy read, social story, first ... then, identify staff who can sign
- use accessible language, e.g. jargon free

### Proactive

- de-sensitisation work, e.g. getting somebody used to tolerating a dressing before their hospital appointment which will include minor surgery
- nasal flu immunisation instead of a vaccination if your relative does not like needles
- arrange a pre visit
- do necessary paperwork beforehand to reduce the waiting time

### Working in partnership

- allow family carers to be with their relative including outside visiting hours
- consult with family carers and other health care professionals to gain a clear understanding of what reasonable adjustments are required
- make sure all relevant information about your relative is made available in advance, e.g. communication passport, hospital passport, health plan

Read this factsheet or watch these two video clips which are part of the Mencap Treat Me Well campaign:



[Click here to read the factsheet from the Challenging Behaviour Foundation](#)



[Click here to watch the first video clip](#)



[Click here to watch the second video clip](#)



[Click here to read more about the Treat Me Well Campaign](#)

**Making reasonable adjustments for patients with a learning disability is G.R.E.A.T.**

**G**ive me more time!

**R**epet yourself!

**E**ffective communication!

**A**ccompanied!

**T**hink team!

### The Mental Capacity Act and medical treatment

If your relative is aged 16 years old or over, health care professionals must seek their consent to any treatment first. Without proper consent their actions could be illegal.

To establish whether your relative has capacity to consent to treatment, a GP or other medical professional must carry out an assessment. For your relative to be judged as having capacity they must be able to:

1. Understand the information given to them to make a decision e.g. what the test is, why they need it, what it will involve, what are the benefits or its risks etc.
2. Remember that information long enough to be able to make a decision
3. Use the information given to them to make a decision
4. Communicate their decision. This could be using words, photos or sign language - whichever way they usually communicate.

Health care professionals can support your relative's involvement in any decision making by:

- communicating using a method they understand
- giving them more time to process the questions
- seeing them in familiar surroundings such as their home
- seeing them at a time they are likely to be responsive

If your relative is over 16 years and has been assessed as having the capacity to make a

particular decision and can understand the risks and benefits but chooses to refuse medical tests, the professionals or you will have to respect their decision and not force them to change their mind.

If your relative has been assessed as not having capacity to make the decision for themselves, then others will have to act in their best interests. This involves looking at what would happen if they did not have the recommended medical treatment and the alternatives.

It is a legal requirement for professionals to consult family carers if their relative has been assessed as lacking capacity to make a decision. Health care professionals must ask for your views (and that of others involved in your relative's life e.g. siblings) about what you think is in your relative's best interests and take this into account when making any decisions. You may not be consulted if the treatment required is considered an emergency. Steps should also be taken to involve your relative in as much of the process as possible.

Some hospitals have a Mental Capacity Act assessor. They ensure that the Mental Capacity Act is being followed by:

- making sure that lack of capacity is not being assumed
- breaking down each part of somebody's treatment plan to ensure that a blanket decision about capacity is not being applied
- confirming that any decisions made are in your relative's best interests
- involving all the relevant people, including family carers

The role of Mental Capacity Act assessor usually sits alongside the Learning Disability Liaison Nursing team and safeguarding.

Decision makers do not have to follow your views if they believe they are not in the best interests of your relative. If you disagree with the decision suggested by professionals, you can apply to the Court of Protection and a Judge will decide whether the treatment should be given.

## Family Carer Advocacy Resource

If you want to make sure that your views are listened to by professionals, you can apply for a Deputyship to the Court of Protection. The Deputyship for Health and Welfare may allow you to make decisions about health and welfare including medical treatments on behalf of your relative if it is included in the Deputyship order.

### Read Ian's story about how applying for Deputyship allowed him to address his son Adam's physical health needs:

[Click here to read Ian's story](#)



[Click here for an example of a good practice flowchart](#)



## Advocacy and health

### Self-advocacy

If your relative has been assessed as having the capacity to agree or disagree and they understand the benefits and risks of any proposed medical treatment, they can represent themselves. Your relative can still ask for support from you as their family carer, another family member, friend or advocate. They are entitled to ask for reasonable adjustments.

### Family carer advocacy

If your relative has been assessed as lacking capacity for a particular treatment, then you can represent your relative's views unless there has been an identified conflict of interest.

### Independent Mental Capacity Act Advocate (IMCA)

If there is no one available to represent your relative or there is a conflict of interest, then an IMCA advocate may be asked to represent your relative's views. Even if you have chosen not to represent your relative, the IMCA advocate should still consult you and others interested in your relative's welfare.

### Independent Mental Health Act Advocate

If your relative is detained under the Mental Health Act they have a statutory (legal) entitlement to an IMHA Advocate. The IMHA Advocate can support them to raise any concerns related to their emotional, mental and physical health, e.g. the medication prescribed for their mental health, requesting dental treatment, pain related to a new (constipation) or long-term health condition (diabetes).

### Further information:

Use this this resource as a checklist to make sure all your relative's health needs are being met and what needs to be in place to ensure that they can access health care settings:



[Click here to read the resource](#)

Read this resource which is part of Mencap's Treat Me Well campaign. Although it is described as a resource for people with profound and multiple learning disabilities the information is still relevant:



[Click here to read the resource](#)

Use this link for advice and guidance about physical health and autistic people. There is also information for family carers:



[Click here to read more](#)

This article provides a personal account of the challenges an autistic woman experiences with food and eating. She discusses the sensory aspects of eating, the relationship between anxiety and controlled eating and how these can be understood and supported by those around her.



[Click here to read more](#)

## Family Carer Advocacy Resource

This online resource hosted by the Challenging Behaviour Foundation provides information and guidance about the use of psychotropic medication to manage behaviour described as challenging. It was developed as part of the Stopping The Over Medication of People (with a learning disability, autism or both) project :



[Click here to access the resource](#)

Read Autistica's report Happier, Healthier, Longer Lives here. It provides information about the emotional and mental health experiences of autistic people, the causes and what can be done to address this:



[Click here to read the report](#)

This link provides information about trauma and support for your relative:



[Click here to read more](#)

Read NHS England's National Plan – Building the Right Support. The right care and support should promote your relative's physical, emotional and mental health:



[Click here to read the plan](#)

This good practice guide from the National Autistic Society provides examples of reasonable adjustments for talking therapies:



[Click here to read the guide](#)

This link provides information about Post Traumatic Stress Disorder and Autism



[Click here to read more](#)

Visit this link from the National Autistic Society for advice and guidance about different mental health diagnoses:



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Read this guide 'Supporting people living with autism spectrum disorder and mental health problems: A guide for practitioners and providers' written by Mind



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## Family Carer Advocacy Resource

Books Beyond Words has a series of books about emotional and mental health:



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This guidance covers preventing, assessing and managing mental health problems in people with learning disabilities in all settings (including health, social care, education, and forensic and criminal justice):



[Click here to read the guidance](#)

Read this article from Learning Disability Today about improving the opportunities for people with a learning disability to be involved in sports and the benefits:



[Click here to read the article](#)

This report looks at what people with a learning disability, autism or both experience when they need physical health care and treatment in hospital:



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