Huntington's Disease Association

# Social work with adults living with Huntington's disease

BASW
The professional association for social work and social workers

EHDN EUROPEAN HUNTINGTON'S DISEASE NETWORK
Advancing Research, Conducting Trials, Improving Care

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# Contents:

# Author

The Huntington's Disease Association is the author of this guideline on social work with adults who have Huntington's disease.

An earlier version of this guideline was published by the British Association of Social Workers (BASW) as 'Social Work with Adults who have Huntington's Disease: A Practice Guide'.

The views expressed in this guideline are those of the Huntington's Disease Association and not necessarily those of the BASW.

# Community reviewer

Allan Adams

# Introduction

Social workers may come across people living with Huntington's if they undertake:

- Adult care assessments and reviews
- Mental capacity assessments
- Adult safeguarding functions
- Have specialist roles in hospital social work or palliative care; or are Approved Mental Health Professionals (AMHPs) conducting Mental Health Act assessments.

A social worker may also encounter Huntington's disease when dealing with a child safeguarding issue, for example, if a parent of a 'child at risk' is living with Huntington's disease.

# General information

### Symptoms of Huntington's disease

A common physical symptom is a change in movement, including new involuntary movements and impaired voluntary movement. The involuntary movement is known as chorea and is perhaps the most obvious symptom of Huntington's disease. However, there is considerable variation in the severity

of chorea amongst people with Huntington's disease.

Most people with Huntington's will experience problems with their speech, which will become increasingly difficult to understand as the disease progresses. Swallowing problems are extremely common, and it is likely that a modified diet and fluids will eventually be required. It may get to the point that a person is not able to swallow safely, meaning alternative methods of feeding need to be explored.

Unintended, and sometimes rapid, weight loss is common in people with Huntington's disease.

A person with Huntington's disease can experience changes to their thinking years before they have obvious physical symptoms. The person may appear as normal but actually be struggling with their thought processes. Over time, these cognitive problems can become more severe.

People with Huntington's disease commonly experience low mood (which may be diagnosed as depression) and anxiety. Personality changes can also occur, which can contribute to irritability, behaviour perceived as aggressive, disinhibition and apathy.

It is common for people with Huntington's disease to develop a degree of lack of awareness or insight into their condition. As a consequence, they may be unwilling to accept help as they are unable to see the need. Perseveration is a common difficulty in which a person with Huntington's can 'get stuck' on a particular thought or action, and struggle to disengage from it.

Further information about Huntington's disease symptoms is available from the Huntington's Disease Association (see 'resources' below).

**Multi-disciplinary team care**

Working collaboratively with other professionals is essential to meeting needs, managing risk and safeguarding someone with Huntington's disease.

These needs may fall into several areas and will change over time.

Many people struggle to keep track of different professionals' involvement.

There must be robust communication and coordination among healthcare professionals, social workers, and other relevant services to provide comprehensive and coordinated support.

The services that a person with Huntington's disease may need additional support from include:

- A specialist Huntington's disease clinic
- Mental health services
- Speech and language therapy
- Dietetics
- Physiotherapy
- Occupational Therapy
- Neurology / neuropsychiatry
- Support from the Huntington's Disease Association

Consider coordinating, becoming part of, or maintaining contact with the multidisciplinary team to ensure that the relevant professionals are involved and working together. Multi-agency meetings are useful in managing support for a person with Huntington's disease.

### Continuing healthcare (CHC) funding

As Huntington's disease progresses, a person is likely to need a higher level of support and specialist intervention. This is because of the increase in the complexity and intensity of the condition.

Consider completing a CHC Checklist.

Ensure there is specialist input during CHC meetings to capture the risks and complexities of the person's needs.

### Supporting a person who is living with Huntington's disease

People with Huntington's disease often struggle to adapt to new situations.

If you have a new service user who is living with Huntington's disease, consider working with a professional who already knows them well, such as a named nurse or clinician, a previous social worker, or a Huntington's Disease Association Specialist Adviser.

This can increase understanding of how to work best with the person and reduce disruption to them and their family.

### Supporting other teams

Share resources with other professionals caring for the person if they lack experience working with someone with Huntington's disease.

### Empowerment and advocacy

Consider referring the person to an advocate and involve them in decision-

making processes as much as possible. Consider the impact of cognitive changes on their ability to engage in decision-making processes, so that appropriate support can be put in place.

### Planning for the future

Encourage discussions around advance planning to help people make their own decisions for the future, such as making a Lasting Power of Attorney (LPA), an advance decision to refuse treatment, and a living will.

### Education and training

Attend education and training to improve understanding and knowledge around the management of Huntington's disease, such as webinars provided by the Huntington's Disease Association.

Ensure any agency / carer / care home supporting someone with Huntington's disease has the required skills and training. Signpost to the Huntington's Disease Association, which has resources on a range of topics affecting people with Huntington's disease, which are not covered in this guideline. More in-depth paid-for training is also available.

# General principles of social work for adults with Huntington's disease

Symptoms often vary among people with Huntington's disease, even within the same family. It is important not to make assumptions about someone based on their diagnosis.

Ensure you have a basic understanding of the general characteristics and challenges of Huntington's disease before working with a person by:

- Recognising the physical, cognitive and mental health changes, and how these interact and lead to behavioural change. Consult resources from the Huntington's Disease Association website, and where necessary, seek more specific advice from a clinician
- Being aware that mental health and cognitive changes can start long before physical changes and are likely to be one of the main things that affect a person's activities of daily living and functioning
- Understanding that it is a genetic and life-limiting disease. Many people have watched a parent (and possibly other family members) have this disease and cared for them for years. Most people have grown up

knowing that they had a 50% chance of inheriting the disease. There is also a lack of public understanding of the disease and a historic reluctance of some families to talk about it, creating stigma and difficulties engaging with help.

- Being aware that there are situations where someone does not have a family history of Huntington's disease

It is good practice for the person to have a named professional supporting them (e.g. a specialist nurse) and to attend a Huntington's clinic. If the person has a named professional, ask for their involvement in supporting social work practice and patient care.

Huntington's is a long-term, progressive disease. Long-term case management to end of life is recommended.

Keep staff consistent where possible, as changes to staff can increase the risk of non-engagement with services and self-neglect. This may increase the level of intervention and formal support needed in the long term.

Huntington's disease causes multigenerational loss and trauma. A key role is to build trusting relationships with families to enable them to accept support. This process starts by listening to family members and taking time to understand the individual's specific needs and who they are as a person. Family members will often provide the majority of care for the person and offer valuable insights into how to work with them effectively. For some people with Huntington's disease, it can take a long time to develop a relationship with a professional and to accept support. This can be due to a reduced or absent level of insight into their needs.

# The role of the social worker in supporting someone with Huntington's disease

### Adult Care Assessments and Reviews

The role of the social worker in supporting someone with Huntington's disease and their family should include assessment, care planning and review in line with the relevant legislation and guidance[1].

Assessments are stronger and more robust if professionals include existing

[1] The Care Act 2014 in England, the Social Services and Well-being (Wales) Act 2014 in Wales, the Social Care (Selfdirected Support) (Scotland) Act 2013 in Scotland and the various legislative acts including the Health and Social Care Reform Act 2009 in Northern Ireland.

recorded information and contact any key professionals who, currently or previously, worked with the person. Carrying forward historical information can support effective risk management. Before sharing personal information, ensure you are permitted to do this under UK GDPR (General Data Protection Regulation).

Establishing a positive relationship with the person and their family (where applicable) is an important first step. Take time to get to know them and understand their needs. Recognise that a person's insight and understanding of their own symptoms and needs may be affected by their condition.

Huntington's disease is a fluctuating and progressive condition, and it is not always possible to predict how or when a person's needs may change. Consider undertaking early or additional reviews to manage and monitor this.

The person may have limited insight into changes in their needs. Professionals need to be proactive and flexible in their approach to care management. Guidance on how to implement this is provided later in this guideline.

A person may decline an assessment of care and support needs (Care Act 2014, section 9). However, a local authority still has a duty to assess those needs if there is evidence the person is experiencing or is at risk of abuse or self-neglect (Care Act 2014, section 11). The NICE guideline on social work with adults experiencing complex needs states that 'social workers should respect people's rights to make decisions that they (the social worker) perceive as risky or unwise when the person has capacity to do so. Do not use such decisions as a reason to refuse care'.

**Personalised Care Planning**

Many people with Huntington's disease struggle with making complex choices. Ask specific and realistic questions (e.g. 'We would like to try a cleaner for you, would that be OK?' rather than 'What do you want?').

Huntington's disease makes it harder to plan, organise, initiate activities, and problem solve. People may not always respond to calls, letters or visits. This should not be taken as a refusal to engage – it may be a sign of disease progression. Explore reasons why somebody is not engaging, e.g. is it related to other aspects of their life, such as abuse? Consult with other members of the multi-disciplinary team and ask the person appropriate questions about

their lack of engagement.

Consider contacting the person at different times of the day and using different methods. Some people prefer text or email communication, because it gives them time to process information and respond at their own pace. However, from a safeguarding perspective, recognise that it could be someone else sending / responding to texts and emails.

Home visits are important to help build a relationship and understand a person's living situation. They provide an opportunity to observe and respond to body language and to be confident of which other people are present (not always possible on a phone call). Persistence is often required as people may find it difficult to keep track of appointments. Patience is also required to gain trust.

People with Huntington's disease can find it difficult to deal with changes or unexpected events, such as a change of plan or postponing a meeting. Giving adequate notice of a visit and not changing the agreed time or arriving late can help to build trust. Consider whether a joint visit with a person they trust would be beneficial.

Some people with Huntington's disease may become irritable, frustrated or angry in response to certain triggers. They may struggle to contain these feelings at times. This can be challenging for family members as well as for professionals and care providers working with them. Consider taking a colleague with you to assessments for support and safety, where an increase in agitation or volatility has been highlighted. Also, determine whether support from mental health services may be needed.

Understanding and avoiding these triggers is key to good communication and the acceptance of support.

Do not offer choices if it is not certain they will be available (e.g. offering a specific care home which is then too expensive). A person with Huntington's disease is at risk of becoming fixated on an option and then struggling to accept any alternative.

Avoid covering multiple issues in one assessment, as this can be overwhelming for someone with Huntington's disease. Limit it to one or two topics.

A gentle introduction of support is more likely to be accepted. Someone may initially accept help with bills, shopping or cleaning, but not personal care. If low-level support is introduced, then it can be developed into a larger care package. Encouraging someone to accept small amounts of help early on could make it easier for them when the condition has progressed and

they require more help.

In the early stages of the disease, people often start to need help with administrative tasks such as remembering appointments, opening letters and paying bills on time. This support, such as from a support worker or personal assistant, can help avoid a crisis as the disease progresses.

Assessing a person with Huntington's disease can take time due to communication difficulties and slow cognitive processing of information. Do not take their first response to questions at face value; check with them that they have understood.

People may take longer to complete tasks due to this slower processing and will need extra time. This is important to consider when arranging a care package. Care packages risk failing if they do not provide adequate time for a person with Huntington's disease to complete tasks.

Sometimes people with Huntington's become 'stuck' on certain ideas and find it difficult to move on. This is known as perseveration. For example, a person could become obsessed with a particular item, such as bottles of water, and buy them in excess. Someone with Huntington's disease may have compulsions that take the form of repetitive behaviours and actions that are associated with an obsessive thought. They may also become obsessed with intrusive thoughts that cause them anxiety. Arguing with the person is unlikely to be effective, and they probably will not understand why you think they are being unreasonable.

Consider helping the person find a new, healthier pursuit to turn their attention to. Encouraging them to become passionate about an activity may be helpful. Compromising, by agreeing to dedicate some time to the idea that they are 'stuck' on, in exchange for them considering new ideas, could also be a helpful tactic. Routine and consistency are important for people with Huntington's disease, and a care plan needs to support this. Consistency in the timing of care and familiarity with the people providing care can make it easier for someone to accept essential support.

Develop detailed emergency plans that account for the behavioural and cognitive challenges of Huntington's disease, ensuring continuity of care and support during crises. It is important that caregivers have contingency plans in place.

If a crisis occurs, ensure that the person's immediate needs are met and assess their ability to stay safe and well in the longer term. Document that

the management of long-term risk has been considered.

Regularly review and update care plans, risk assessments and capacity assessments to reflect the progressive nature of Huntington's disease and the changing needs of the person and their family.

# Assessing mental capacity in people with Huntington's disease

**General principles**

A mental capacity assessment is advised at every contact to identify whether the person's specific decision-making skills, regarding their health and care needs, are present or impaired. For example, low-level decisions and orientation may imply that the person has capacity, but in relation to decisions about care and support needs, they may not be capacitous. There is a difference between making a poor / unwise decision and not being able to weigh up or consider data to make any decision relating to care, support or risk. A clinician who is familiar with Huntington's disease may be able to support this process.

Unlike conditions such as Alzheimer's disease, memory and language function are often superficially well-preserved in people with Huntington's. This makes identifying problems that the person may experience with 'weighing up' subtle and more difficult to detect. As a result, capacity assessments for people with Huntington's disease are some of the most technically complex.

People with Huntington's disease may have impaired capacity for a number of reasons. The primary reason is related to the inability to 'weigh up' information sufficiently to make a decision. Communication difficulties can make it harder for a person to express their decisions. Use the following strategies to maximise communication:

- Giving relevant information in 'bite-size' chunks
- Allowing time for information to be processed
- Allowing time for the person to talk
- Using favoured communication methods, such as communication boards
- Picking a time during the day when cognition is greatest. Some people with Huntington's disease sleep poorly and so struggle at certain times of day

This process can require careful preparation and, where appropriate, the intervention of a speech and language therapist. Where someone's speech is affected, it is also helpful to involve the person who best knows how to communicate with them.

**Preparing for the capacity assessment**

Before the assessment, ensure you have identified the 'relevant information' for the decision(s) being assessed. Make sure you have it written down as prompts for your assessment.

The 'relevant information' is the information that the person has to understand / retain / use when making the decision. There is specific case law in relation to issues including where a person lives, what care and support they have, concerns about exploitation, behavioural difficulties and any online concerns. Your local Adult Safeguarding and Deprivation of Liberty Safeguards (DoLS) team lead should be able to assist with getting up-to-date information on this.

Hold more than one session if needed to enable findings to be considered between sessions.

This is particularly important for major decisions about welfare (such as accepting care or a move to a care setting), or where there are significant concerns about self-neglect or vulnerability.

Involving a person who is familiar with the person and who they feel comfortable with can help maximise their capacity to make a decision.

**Weighing up the pros and cons**

Make an estimate before the assessment about how much 'weighing up' would be sufficient. The person being assessed should consider both the common and the serious consequences of a decision. People with Huntington's disease might have specific cognitive problems, which could impair this process. These include:

1. **Lack of 'future visioning':** Some people with Huntington's disease find imagining the future difficult, which can make decision-making challenging. Present possible future consequences and test reasoning about them, rather than asking people to imagine scenarios themselves.
2. **An inability to follow through and act on a decision:** The person may be able to say what they would do if they had a fall (e.g. 'I'd press my alarm'),

but in reality would not be able to use their alarm because it is upstairs and never with them.

3. **Unable to recognise their own difficulties:** Explore anything that the person says that contradicts reliable, factual observations of carers or family. Self-neglect and personal safety are common areas of concern.

**Executive functioning**

Huntington's disease affects executive function. 'Executive function' is an umbrella term relating to the broad range of cognitive skills that help us function in day-to-day life, allowing us to stay safe, manage day-to-day tasks, and get things done. These include normally automatic abilities such as decision-making, problem solving, planning and organising, multi-tasking, generating motivation, retrieval of information, emotional control, flexibility in thinking, judgement, being able to switch tasks, and applying these in the decision-making moment.

It is more difficult to assess capacity in people with executive dysfunction.

Some people with Huntington's disease may struggle with initiating tasks as well as problem-solving. This can mean that although they may understand something in principle, being realistic about their own abilities or following through to act on a decision is difficult. Consider evidence of these factors alongside what someone may be able to communicate, as part of a mental capacity assessment. For example, someone may be able to talk through how they would go food shopping and the importance of eating well, and decline support with these tasks. However, if they are continuing to lose weight, do not have food at home and are requesting emergency food parcels, they may not be able to implement the decision in practice.

Consider the following points from the 2018 NICE guideline on decision-making and mental capacity, where guidance is given on assessing capacity in people with executive dysfunction:

- **Real-world observation:** Structured assessments of capacity, such as an interview, may need to be supplemented by real-world observation of the person's functioning and decision-making abilities
- **Consulting others:** Use information gathered from paid carers, family, friends and advocates to help create a complete picture of the person's capacity to make a specific decision and act on it
- **Making an unwise decision:** At times, the person may wish to make a decision that appears unwise. As confirmed by the third key principle of the Mental Capacity Act 2005, a person is not to be treated as unable to make a decision merely because he or she makes an unwise decision.

The Mental Capacity Act Code of Practice states that 'There may be cause for concern if somebody repeatedly makes unwise decisions that put them at significant risk of harm or exploitation … These things do not necessarily mean that somebody lacks capacity. But there might be a need for further investigation, taking into account the person's past decisions and choices.'

The 'frontal lobe paradox' describes the situation where people with frontal lobe damage can perform well in controlled settings such as interviews or tests, but struggle significantly in real-world situations. If professionals are unaware of this when assessing mental capacity, then there is a risk of overestimating the person's ability to live independently. The frontal lobe paradox is often used in reference to patients with acquired brain injury. Although the changes in the brain are different from those in Huntington's, resources and guidance on the frontal lobe paradox can be helpful.

If a person refuses to cooperate fully with an assessment, then seek advice from someone with experience in Huntington's disease and capacity assessments. Many aspects of the cognitive impairment and psychiatric symptoms in Huntington's disease cause such refusals. These kinds of difficulties usually affect capacity for the decision at issue, as well as capacity to engage in discussions about it. This is particularly important when considering the issues about repeatedly refusing care, referred to earlier from the Mental Capacity Act Code of Practice. The presumption of capacity must be balanced thoughtfully against those repeated refusals and the nature of the condition.

**Regaining capacity**

Huntington's disease is progressive, which means that core cognitive impairment is unlikely to improve significantly. It may be possible to address factors that may worsen cognition, such as infections, pain, depression and irritability. Improving care and support may also help with irritability. Advice from a specialist nurse, neurologist or neuropsychiatrist may be needed on how to improve this. Ensuring any medications are being taken as prescribed may help to maximise someone's capacity. In general terms, the more advanced the level of cognitive impairment, the less likely that the person will regain capacity.

Sources of information regarding assessing mental capacity in someone with executive dysfunction are included below (see 'references').

### Approaching Best Interests decisions

Unless it would be contrary to the person's best interests, work with paid carers, family and friends, advocates, attorneys and deputies, to find out their values, feelings, beliefs, wishes and preferences in relation to the specific decision, and to understand their decision-making history.

In some cases, the views of the interested parties may differ from those of the person or the decision-maker. However, this does not necessarily mean it would be contrary to the person's best interests to consult them.

There may be ways to promote autonomy and minimise risk, which require creative problem-solving and a person-centred approach based on what is important to that person.

For example, if going out independently is important, but someone is leaving the door unlocked, could a fob-entry system be tried? If smoking is an important part of someone's routine, could fire safety equipment make this safer? If someone is no longer safe to drive, how can they be supported to access the community and avoid isolation?

# Support for family members, children and carers

### Support for unpaid carers

Offer a carer's assessment and signpost to local support. Unpaid carers may benefit from opportunities to meet with others in a similar situation and share experiences. These opportunities are available through the Huntington's Disease Association. Signpost to information about Huntington's disease (also available through the Huntington's Disease Association).

Be aware that the person with Huntington's disease may be particularly dependent on one individual (such as their spouse) and not want others involved in their care. Look for early opportunities to introduce additional support and ensure there are contingency options in place, such as respite. Failing to do this can place significant pressure on family members. Consider the emotional impact of living with a person with Huntington's disease, particularly if they are experiencing emotional dysregulation.

Recognise that some carers may be experiencing physical and verbal abuse. If so, consider what support is needed. This could include safety planning, domestic violence support, and involving safeguarding where children or other adults at risk may be involved.

**Support for children**

Understand the impact on children in the family. Ensure that parents are aware of support available from the Huntington's Disease Association Youth Engagement Service (HDYES), as well as local support through schools and other organisations. HDYES can support parents in having initial discussions with children about Huntington's, so they feel more confident in starting the conversation.

Support from charities that support young carers can be beneficial for children who are in a caring role.

Be aware of children's needs and liaise with children's services, where appropriate.

Consider whether the person with Huntington's disease has the ability to support the child to attend and take part in school. For example, can they ensure the child gets to school on time and has the correct uniform?

If necessary, consider alerting the school to the situation at home so they are able to support and monitor the situation. The Huntington's Disease Association Youth Engagement Service (HDYES) can help with this.

# Adult safeguarding

There may be additional factors to consider around adult safeguarding when working with people with Huntington's disease.

Due to cognitive changes, a person may display more risky behaviours or be at higher risk of drug or alcohol misuse than the general population.

Cognitive changes and mental health difficulties can also make people with Huntington's disease vulnerable to exploitation.

Understanding a person's lived experience will help to identify levels of dependency on others and risks.

Some people with Huntington's prefer to have a friend or family member present to support with communication and understanding, but if you have concerns around potential abuse, try to create opportunities to talk to

someone alone.

Be aware that someone might not recognise that they are being abused.

To safeguard people with Huntington's disease, explore the reasons behind non-attendance at appointments or a lack of engagement with services.

Communication with other professionals who are involved is key. This is for ongoing support and care, but also to notice and share unusual behaviour (e.g. new people appearing and taking on a caring role, refusing home visits). It should not become 'accepted behaviour' that someone cancels / misses appointments. In these situations, there should be a process for escalating concerns (e.g. how does a care agency inform Social Services of a concern?).

If a person has not been seen, one option is to ask the police to conduct a Safe and Well check. First, consider whether there is another person who could visit to avoid frightening the person unnecessarily. If the police are contacted to conduct a Safe and Well check, then consider whether there is someone known to the person who could accompany them.

A good assessment of unpaid carers is necessary to reduce the risk of neglect and abuse. If new people start to live with and / or care for the person with Huntington's disease, questions should be asked, e.g. how long they have known each other and how they have become a housemate / carer? A person who offers care and support may not always be appropriate for this role. Consider this holistically – is the person clean and appropriately dressed? Is the property being kept in good condition?

Explore changes, such as new anti-social behaviour at the person's property. The person with Huntington's disease may be a victim rather than a perpetrator.

Difficulties with emotional regulation, problem-solving and impulse control may cause conflict in personal relationships, sometimes leading to issues with antisocial behaviour. Please see the section on carer support above.

Huntington's disease symptoms can make it harder to manage finances, leading to potential risks around budgeting, debt and financial exploitation. Early support in these areas, such as future planning for finances, can help to manage these risks.

Managing finances, property / properties and wider practical affairs are amongst the most cognitively complex things that people have to do. As a result, this is often the first area where people may lose capacity.

Along with providing appropriate support if the person is struggling with rising debt, consider their capacity to make financial decisions. Rising debt is a potential indicator of abuse and should be explored. Often, there is no appropriate individual to support the person with Huntington's disease in managing their finances. In these circumstances, corporate appointeeship should be considered. This would enable the local authority to manage the person's finances, if deemed appropriate.

A person's lack of insight into their symptoms can lead to problems seeking or accepting essential support. This can lead to self-neglect, making it harder for the person to manage their personal hygiene, home environment and health needs. Self-neglect can significantly increase the risk of injury. For example, if the person experiences a deterioration in their swallowing but does not recognise this and modify their diet appropriately, they may be at risk of choking and aspirating.

Self-neglect and vulnerability may be serious and urgent safeguarding issues - for example, choking and aspiration pneumonia are common and preventable causes of premature death in people with neurodegenerative conditions.

Self-neglect should not be considered a 'norm'. Do not assume that any risks arising from self-neglect are no longer a concern because the person has not been willing to accept support from a social worker.

Develop trust and understand the person's perspective when supporting people to manage these risks, and try to find a compromise to reduce risk. This can help enable people to accept essential support and increase their safety and wellbeing.

It is essential that fire risk is assessed, and where appropriate, a Safe and Well check is carried out by the fire service.

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*Dr Mike Layton*

# Resources

### Huntington's Disease Association resources for professionals

The Huntington's Disease Association offers a range of resources to support professionals working with people affected by Huntington's disease.

You can find our resources at **www.hda.org.uk**

Explore the professionals webpage using the search bar to find specific resources. Search "resources".

### Stay informed

Join our professional-only mailing list to receive updates on events, webinars, and new resources tailored to your needs. You can sign-up at **https://www.hda.org.uk/professionals-and-training/**

### Support for children and young people

Find information on our Huntington's Disease Youth Engagement Service (HDYES) by searching for "HDYES" on the website.

# Resources


Alex Ruck Keene KC (Hon). May 2019. Executive dysfunction under the judicial spotlight. Blog: Mental Capacity Law and Policy.

George, M. and Gilbert, S. 2018. Mental Capacity Act (2005) assessments: Why everyone needs to know about the frontal lobe paradox. British Psychological Society (BPS).

Mental Capacity Guidance Note: Relevant information for different categories of decisions. May 2024. 39 Essex Chambers. **N.B. It is important to ensure that new case law has not emerged when referring to this type of guidance.**

NICE guidance is published on **www.nice.org.uk**

Relevant guidance includes:

- NICE. 2018. Decision-making and mental capacity.
- NICE. 2022. Social work with adults experiencing complex needs.

# Notes

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## Get in touch

For advice and support or to speak to a Specialist Huntington's disease Adviser

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