Social Work with Adults who have Huntington's Disease:

A Practice Guide

Huntington's Disease Association

BASW
The professional association for social work and social workers

Introduction

An estimated 8,000 people have been diagnosed with Huntington's disease in the UK. 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

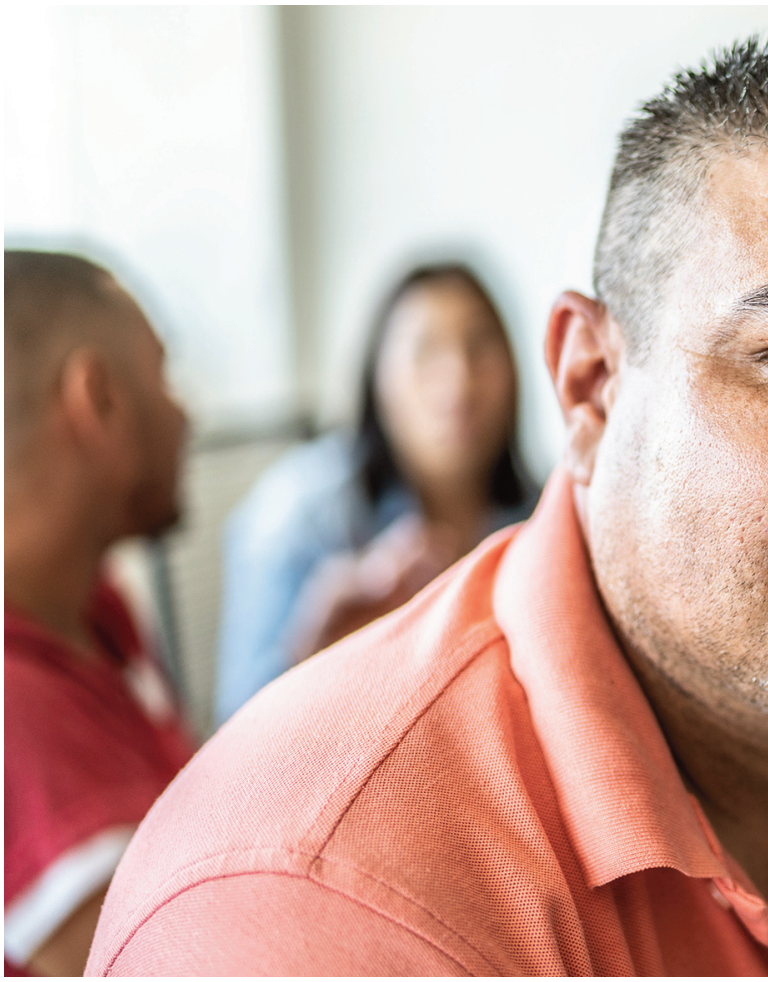
A social worker may also encounter Huntington's disease when dealing with a child safeguarding issue, for example, if a parent of a 'child at risk' is living with Huntington's disease.

What is Huntington's disease?

Huntington's disease, previously known as Huntington's Chorea, is a neurological condition which affects the body's central nervous system – the network of nerve tissues in the brain and spinal cord that coordinate bodily activities. Although there is, as yet, no cure, much can be done to support people with Huntington's disease to manage symptoms more effectively, reduce risk and improve their quality of life.

The symptoms of Huntington's disease vary widely between people. However, changes usually affect three main areas:

- **Physical health:** involuntary movements, poor co-ordination, problems with balance, walking, swallowing and speech.
- **Cognitive:** mental inflexibility, difficulties in thinking and processing information.
- **Mental health:** changes in behaviour and personality, mood dysregulation.

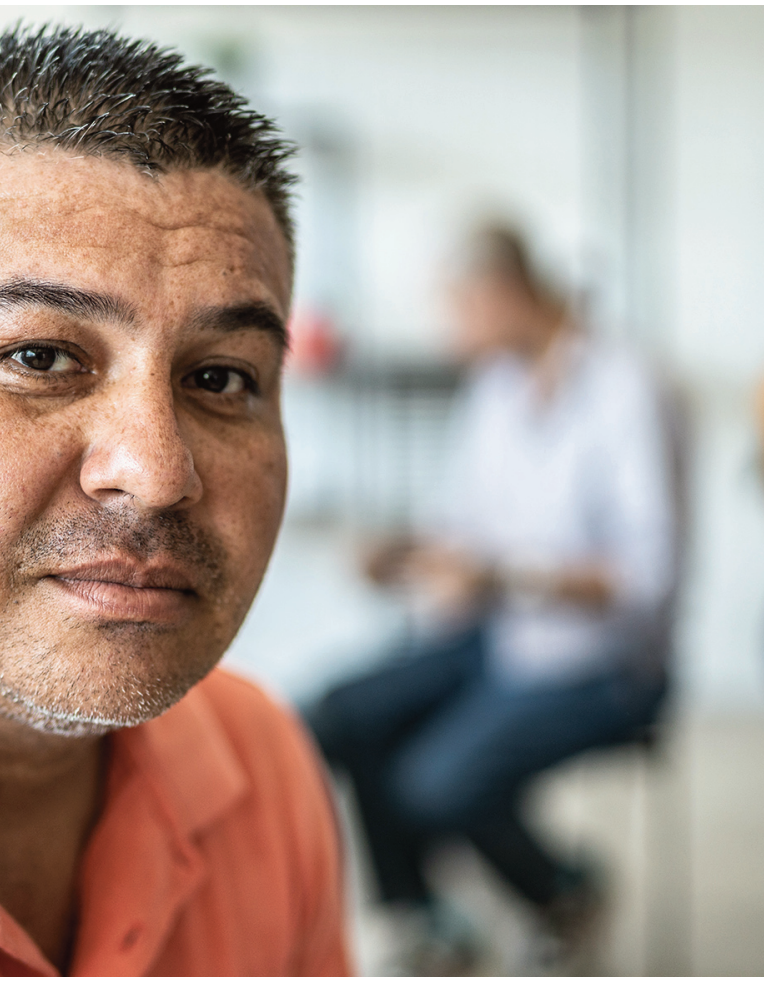


Huntington's disease is inherited from a parent who has the faulty gene. Every child conceived naturally to a parent who carries the faulty Huntington's gene has a 50% chance of inheriting it. People can live for years without symptoms, but if people do have the faulty gene, at some stage they will develop symptoms. Doctors cannot predict when this will be, but symptoms usually develop between the ages of 30 and 50.

Huntington's disease can equally affect males and females. For those who develop symptoms before the age of 20, this is known as Juvenile Huntington's disease, which is rare. Less than 10% of people with the disease will have Juvenile-onset Huntington's disease.

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. Seek advice from a clinician who is familiar with Huntington's disease to support with this.
- 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 impact 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 are situations where someone does not have a family history of Huntington's disease.

It is good practice for the person living with Huntington's disease 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 multi-generational loss and trauma. A key role is to build trusting relationships with families to enable them to accept support.

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 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.

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 with Huntington's disease 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 practice guide.

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 it is thought that the person is experiencing or is at risk of abuse or neglect (Care Act 2014 section 11). 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 need for further investigation, taking into account the person's past decisions and choices."

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".

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.

Personalised Care Planning

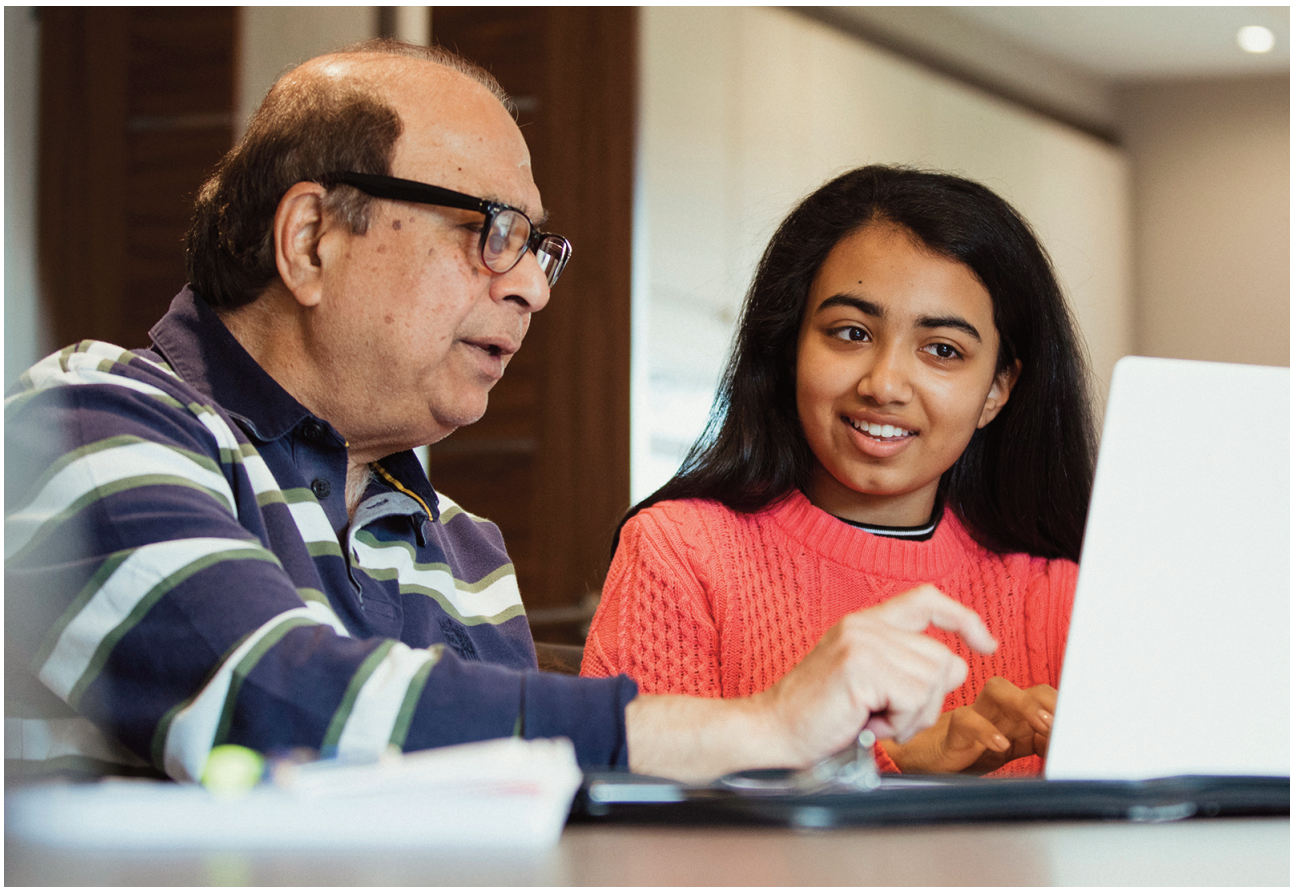
Many people with Huntington's disease struggle with making complex choices. Ask specific and realistic questions (e.g. 'We would like to try a cleaner for you, would that be OK?' rather than 'What do you want?').

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.

---

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



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.

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.

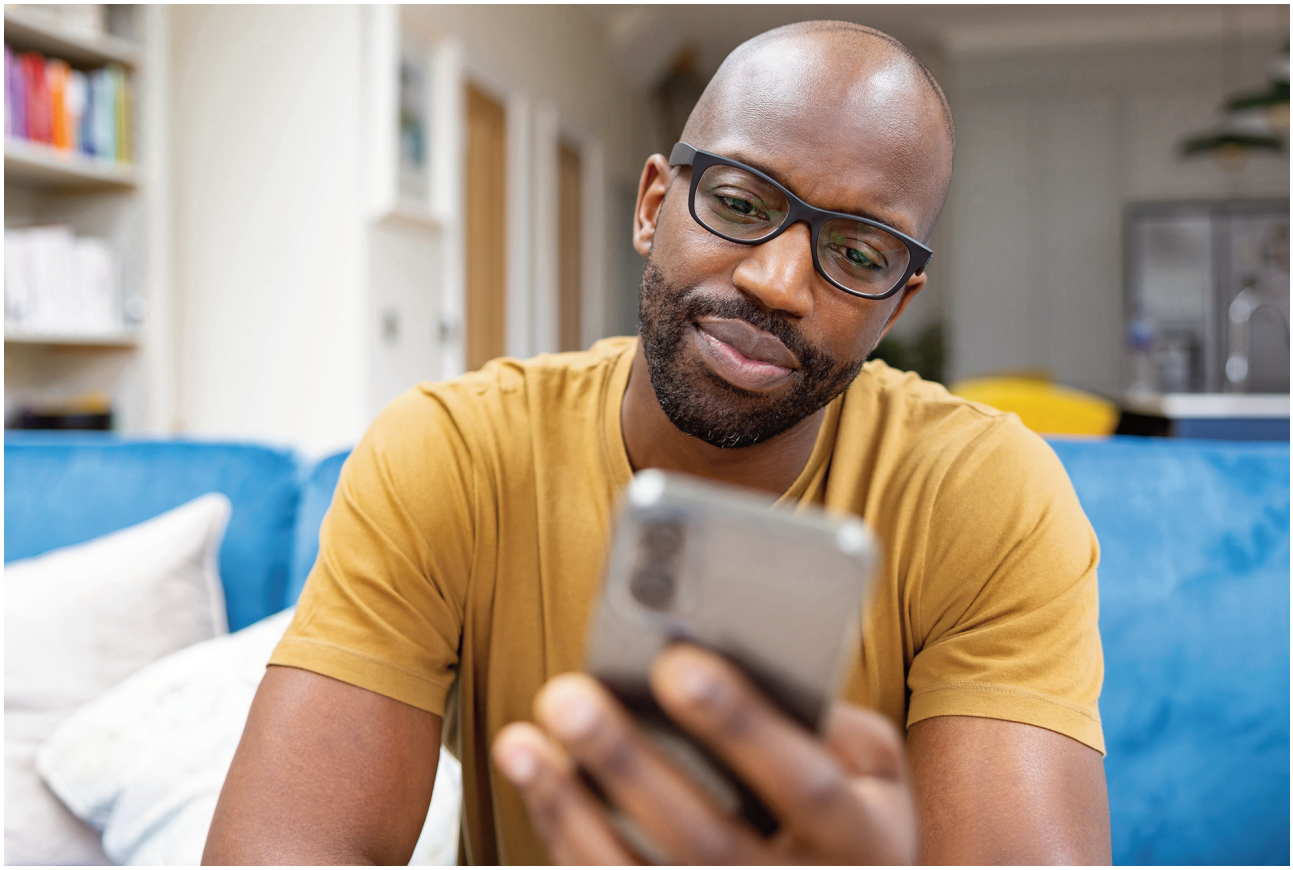
People may take longer to complete tasks due to this slower processing and will need extra time. This is important to consider when arranging a care package. Care packages risk failing if they do not provide adequate time for a person with Huntington's disease to complete tasks.

Sometimes people with Huntington's can get '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 it 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 with Huntington's 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 carers 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 individuals and their families.

Assessing mental capacity in people with Huntington's disease

General principles

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 where 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.

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

Involving a person who is familiar with the person with Huntington's disease 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 spontaneously imagine scenarios themselves.
2. **An ability 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.

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 may be 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 acting 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 a decision in practice.

Our guide on mental illness and mental capacity in Huntington's disease (see 'useful resources' below) provides further information on assessing mental capacity in Huntington's disease.

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?

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 support workers, 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.

  Unless it would be contrary to the person's best interests, work with 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.

- **Making an unwise decision:** At times, the person being supported 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.

Other sources of information regarding assessing mental capacity in someone with executive dysfunction are included under 'useful resources' below.

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.

Create opportunities to talk to someone alone, if potential abuse has been identified.

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

To safeguard people with Huntington's disease, explore the reasons behind cancelling carers, 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, ask the police to conduct a Safe and Well check.

A good assessment of informal 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 have they become a housemate/carer? A person who offers care and support may not always be appropriate. Consider this holistically – is the person clean and appropriately dressed? Is the property being kept in a 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 below.

Huntington's disease symptoms can make it harder to manage finances, leading to potential risks around budgeting, debt and financial exploitation. Early help in these areas can make a significant difference and future planning for finances should be discussed early on.

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 not an appropriate person to support the person with Huntington's disease with 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 should not be considered a 'norm'. Do not assume 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.

General information

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 multi-disciplinary 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.

Working with a new client

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

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

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

Supporting other teams

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

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), 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 free resources for professionals.

Children and carers

Support for carers:

Ensure that carers are offered a carer's assessment and signposted to local support.

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 carers to information about Huntington's disease (available through the Huntington's Disease Association).

Be aware that the person with Huntington's disease may be particularly dependent on one person (such as their spouse) and not want others involved in their care. Look for early solutions to introduce additional support and ensure there are contingency options in place. Failing to do this can place significant pressure on family carers.

Useful resources

Huntington's Disease Association Resources for Professionals

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

Where to find our resources
Visit our website at www.hda.org.uk. You can:
Explore the Professionals webpage.
Use the search bar to find specific resources.

Search "resources"

Key Resources Available
Behaviour and Communication Guide
Care in Advanced Huntington's Disease
Mental Illness and Mental Capacity in Huntington's Disease – A Guide for Mental Health Workers

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

Stay Informed
Join our professional-only mailing list to receive updates on events, webinars, and new resources tailored to your needs.

General Information
You can also access a wealth of general information about Huntington's disease on our website.

NICE guidelines

NICE guidelines are published on www.nice.org.uk
You can search for:
NICE. 2018. Decision-making and mental capacity.
NICE. 2022. Social work with adults experiencing complex needs.

Other resources

Alex Ruck Keene KC (Hon). 2019. Executive dysfunction under the judicial spotlight.

British Psychological Society (BPS). 2018. The 'Frontal Lobe Paradox' and relevance to mental capacity.

Neuro Rehab Times. 2020. Frontal lobe paradox – how can we best help service users?

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 at school. For example, can the person 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.

The Huntington's Disease Association is the author of *Social Work with Adults who have Huntington's Disease: A Practice Guide*.

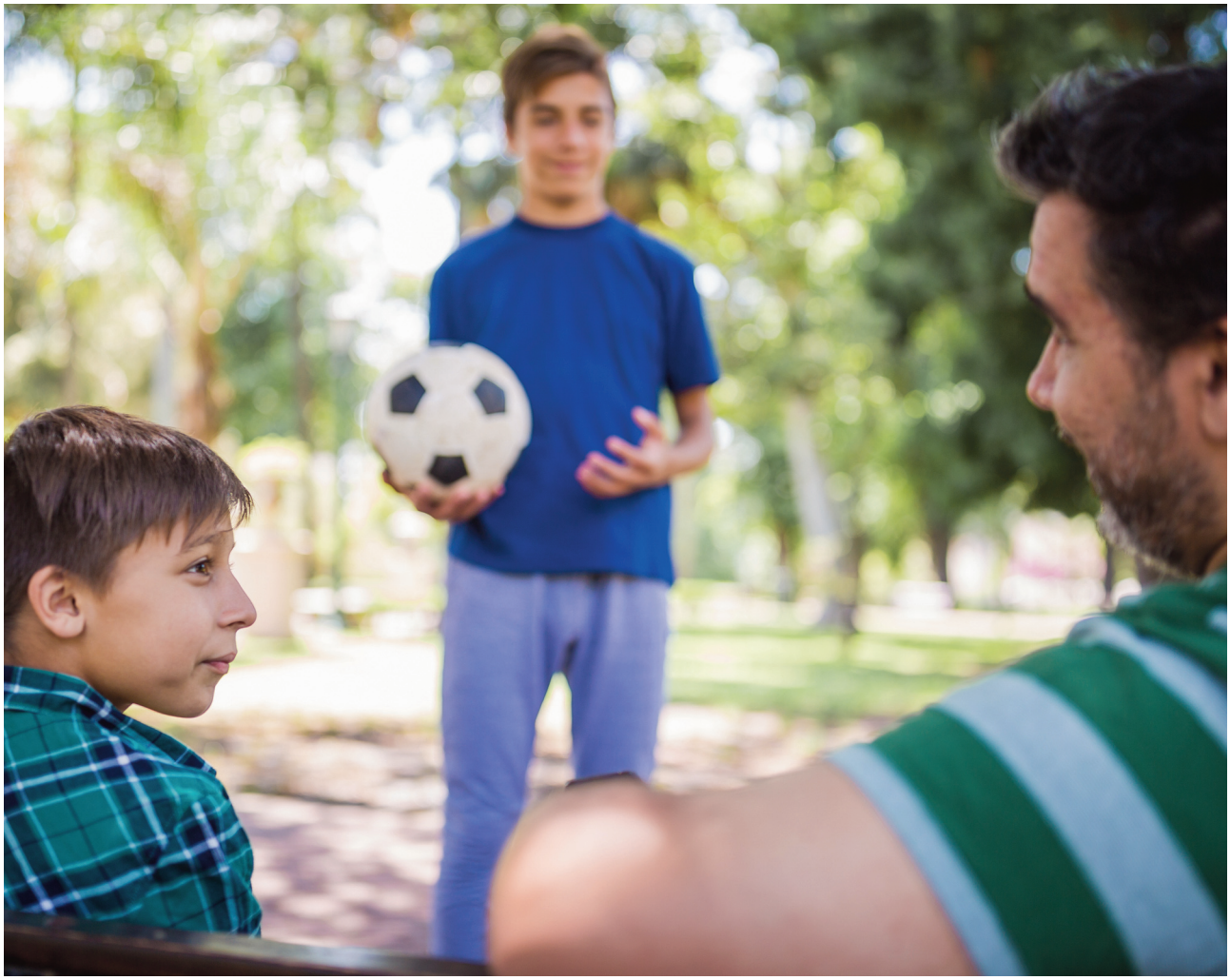
Fiona Chaâbane and Dr Luke Geoghegan edited this resource.

Social Work with Adults who have Huntington's Disease: A Practice Guide is one of a series of BASW Research Findings – publications showcasing evidential research led by university academics, researchers, charities and/or social work service users that offer both significant impact and have practical implications for social work practice.

This report summarises the implications for social work practice from the Huntington's Disease Association.

The report is a resource and consequently the views expressed are those of the authors and not necessarily those of BASW.

All photographs posed by models.



Cite as:
Huntington's Disease Association (2025) ***Social Work with Adults who have Huntington's Disease: A Practice Guide.*** Birmingham: BASW.

www.basw.co.uk

Huntington's Disease Association

BASW
The professional association for social work and social workers