Meeting the 5 challenge

I am worried my family member is getting poor care or being abused, what can I do?



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This factsheet provides information to help you understand what is meant by abuse and poor care and support. It also provides information about who to talk to if you suspect that your family member is experiencing either or both of these things and needs **safeguarding**.

This factsheet includes lots of the information included in 'When things go wrong' by the National Family Carer Network:

www.familycarers.org.uk/resources/by-tag/policy-and-law

Words in **red** are explained in more detail in the glossary at the end of the factsheet.

Abuse and poor care can take place anywhere. Families are often particularly concerned when their family member is far away from home and they are unable to visit regularly.

You may find it useful to read this factsheet alongside factsheet 2 which provides information about what good support and care should look like.

What is meant by 'abuse'

Abuse means illegal, improper or harmful practice. It can take a number of different forms, including:

- physical abuse
- sexual abuse
- psychological or emotional abuse
- financial abuse
- neglect or acts of omission are also forms of abuse.

Abuse or neglect may be deliberate or the result of negligence or ignorance.

The person who is responsible for the abuse is often well known to the person abused. They could be:

- A paid carer or volunteer.
- A health worker, social care or other worker
- A relative, friend or neighbour
- An occasional visitor or someone who is providing a service

"A high quality service means that people with learning disabilities or autism and behaviour which challenges will be able to say.. I am safe and treated with compassion, dignity and respect"

Transforming Care report ¹

¹Transforming Care: A national response to Winterbourne View Hospital, Department of Health, 2012 www.gov.uk/government/uploads/system/uploads/ attachment_data/file/213215/final-report.pdf

- Someone who deliberately exploits vulnerable people
- Someone who uses services

People who use services may intentionally or unintentionally abuse others and may require support to overcome abusive behaviour.

What is meant by 'poor care'

There is no clear definition of poor care and there can sometimes be 'a thin line' between poor care, and abuse and neglect. The bottom line is this: is the person getting the support they need and which has been identified in their care plan as important for their health and wellbeing?

Poor care includes things like not being able to access fresh air, take part in meaningful activities and have nutritious food.

What are restrictive practices and when can they be used?

In some cases the use of restraint or other forms of restrictive practice may be necessary and appropriate to keep your family member or others safe. Where restaint is used, it must be done in the least restrictive way. Any inappropriate use of 'restraint' and other restrictive practices could be regarded as either abuse or poor care.

The investigations after the abuse scandal at Winterbourne View showed that restrictive interventions are not always used as a last resort and that sometimes they can even be used to inflict pain, humiliate or punish. They can also be used inappropriately when staff do not have the right training and support. Both can result in physical and psychological trauma.



Top Tip

If you are unsure if a restrictive practice is appropriate seek advice from a professional with expertise in behaviour that challenges or one of the organisations listed at the end of this factsheet.

For more information:

The Department of Health's guidance on improving care and support for people and reducing the need for restrictive interventions:

Positive and proactive care: reducing the need for restrictive interventions

www.gov.uk/government/uploads/ system/uploads/attachment_data/ file/300293/JRA_DoH_Guidance_on_ RP_web_accessible.pdf

Information about physical intervention training and a list of accredited courses on the British Institute of Learning Disabilities (BILD) website:

www.bild.org.uk/our-services/ accreditation/

Concerns about abuse or risk of abuse

- If at any point you believe your family member is in immediate danger you should contact the police.
- If there is no immediate danger, you should report your concerns about abuse to the local authority in which the person is living, immediately. Each local authority has an adult safeguarding team (sometimes called an adult protection team) – the details should be on your local authority website or you can call them and ask. You should contact the adult safeguarding team if you have any suspicion that someone is at risk of abuse.
- If you do not receive a swift response from the safeguarding team letting you know whether or not they plan to investigate or you are not happy with the outcome, then you may wish to make a formal complaint to the local authority in which the person lives as soon as possible. You can also report your suspicions to the police.
- If the matter is not resolved quickly and decisively by the service provider, the local authority and/or the police, you could approach a community care solicitor who may be able to advise you about the best

- course of action and liaise with the relevant people on your behalf.
- If you are worried about raising an issue, you may be able to get support from your family member's advocate (if they have one), a friend or an organisation that can provide practical and/ or emotional support – take them with you for support at meetings.

You can also consider reporting your concerns to the **Care Quality Commission (CQC)** who inspect health and social care services. The CQC tends to focus on the service as a whole, rather than individual complaints. You may want to register concerns with them so they take these into account when inspecting a service. You can contact them by letter, phone or on their website:

www.cqc.org.uk/content/complain-aboutservice-or-provider



Top Tips

- Listen to what your family member has to say and observe how they appear around the staff that support them.
- Keep a written record of what it is that concerns you. Note down dates, what happened, where you were, and who was involved.
 Gathering all your facts together in this way can be helpful especially if you feel nervous or even a bit intimidated about raising your concerns.
- Keep a copy of all documents relating to your complaint including emails, letters and photos in case you need them at a later date.
- Ask a solicitor if your relative can receive legal aid. Many adults with a learning disability who receive certain benefits and have little or no savings are eligible.
- Do ask questions and challenge if you do not hear the result of the safeguarding investigation or you are concerned about what you are being told.



More Information

'Getting It Right for People with Learning Disabilities: Going into hospital because of mental health difficulties or challenging behaviour. What families need to know!' (NHS England)

If your family member is in hospital and you have a concern, read the section on 'what to do if you have concerns'.

www.nhs.uk/Livewell/ Childrenwithalearningdisability/ Documents/NHS-England-Gettingit-right-for-people-with-learningdisabilities-epublication.pdf

'Making sure your relative is safe' is a free resource pack including a DVD for family carers about safeguarding adults with learning disabilities (HFT).

www.hft.org.uk/Safeguarding



More Information

The Care Act 2014 has brought in stronger duties in relation to adult safeguarding. See the Department of Health factsheet on Adult Safeguarding:

www.gov.uk/government/uploads/ system/uploads/attachment_data/ file/366087/Factsheet_7_-_ Safeguarding.pdf

Check eligibility for legal aid by using the Legal Aid checker:

www.gov.uk/check-legal-aid

What to do if you suspect poor care

If you are worried that your family member is receiving poor care it is important that you raise your concerns and speak up. Organisations like the ones listed at the end of this factsheet may be able to help you to talk through the particular circumstances and provide you with support.

There are different ways of making a complaint depending on who you are complaining to (e.g. a service provider, the local authority, the NHS), and who funds the service, as well as how urgent the situation is.

The nature of the complaint usually determines which organisation to approach. For example, if it is an aspect of the service that is unsatisfactory it may be more appropriate to start with the service provider. If the complaint is broader – i.e. the service is not meeting the needs of your family member (see factsheet 2 on what good support should look like) or you are not satisfied with the response from the service provider, raise the complaint with the local authority or through the NHS complaints process depending on who funds the service.

Raising concerns and making complaints

To a service provider:

 Raise the concern with the person responsible for the issue you have concerns about.
 For example, if your family member is in a specialist hospital or assessment and treatment unit, and you are unhappy about the care or treatment they are getting, you could speak to their Responsible Clinician in the first instance. In a care home, this might be the registered manager.

- Talk to your family member's advocate if they have one. They have an important role in making sure that the concerns and worries of your relative are heard.
- If this does not work you should then look to make a formal complaint.
- To do this, get a copy of the service's complaints procedure. Services that are regulated by the CQC must have a complaints procedure. The complaints procedure should provide information about what to do and who to contact and should give clear timescales.
- Following a formal complaint, if you are still not satisfied with the response from the service provider, raise your concerns with the local authority or NHS (depending on whether the service is providing social care or health care).

To the local authority (about social care)

 Try to resolve your concerns informally by talking to or writing a letter to your family member's Social Worker/Care Manager or another person you are in contact with at the Local Authority. If your relative does not have a Social Worker/Care Manager you can address a letter to the "Duty Social Worker" at the Local Authority.

- The Local Authority may be able to resolve the situation at this stage e.g. if your family member is getting poor care because they require more support than they are currently getting then the Local Authority may carry out a reassessment which could lead to an appropriate package of care being provided.
- If your concerns are not properly addressed through talking to or writing a letter to the Local Authority, then you should consider making a formal complaint.
- Get a copy of the Local Authority's complaints procedure. They must have a published complaints procedure. You should be able to find this on the Local Authority website.
- The complaints procedure should provide information about what to do and who to contact and give clear timescales.
- After you have been through the local authority complaints procedure, if you are still not satisfied, you may want to apply to the Local Government Ombudsman. You can find out more here: www.lgo.org.uk/

To the NHS (about health or any services funded by the NHS)

 Try to resolve your concerns informally by talking to or writing a letter to the relevant person working in the NHS e.g. Clinical Commissioning Group.

- If your concerns are not properly addressed through a discussion or writing a letter, then you should consider making a formal complaint.
- Get a copy of the NHS complaints procedure.
 The relevant NHS body (for example this may be your local Clinical Commissioning Group (CCG)) must have a published NHS complaints procedure. You should be able to find this on their website.
- The complaints procedure should provide information about what to do and who to contact and give clear timescales.
- After you have been through the local NHS complaints procedure, if you are still not satisfied, you may want to apply to the Parliamentary and Health Service Ombudsman. You can find out more here: www.ombudsman.org.uk/



Top Tip

When writing a complaint letter make sure you include your name and contact details. Explain the background facts to the issue, what the current problem is, what you have done so far to try and resolve it, and what solution you are looking for.

Support to make a complaint

Your local PALS (Patient Advice and Liaison Service) can provide you with information, advice and support about complaints about NHS run services. You can find your nearest PALS here or ask at your local hospital:

www.nhs.uk/Service-Search/Patient%20 advice%20and%20liaison%20services%20 %28PALS%29/LocationSearch/363

NHS Complaints Advocacy Service is a free and independent service that can help you make a complaint about the NHS:

http://nhscomplaintsadvocacy.org/

Independent Health Complaints Advocacy is a free and independent advocacy service for people who wish to make a formal complaint about the NHS. It covers the South of England region only:

www.seap.org.uk/services/nhs-complaints-advocacy

There may be other local organisations which can support you with making a complaint. The national organisations listed at the end of this factsheet should be able to signpost you to these.

Further options

Contact a solicitor in order to explore the legal options if you feel that this is necessary. There are specialist lawyers who cover things like human rights law, health and social care/community care law and mental health and mental capacity legislation. They will be able to advise you on the best course of action, correspond with the other parties on your behalf, and represent your family member in court if necessary. You may be able to advise the solicitor as a "litigation friend".

Note: Making a complaint will often be your first attempt to resolve the issue, before starting a claim in court. However, there are sometimes very strict time limits within which you have to start court proceeding if you are going to do so. As a general rule, if the matter is not serious or urgent, make a complaint first. If it is serious or urgent, then you may want to approach a solicitor.

Register the issue with the Care Quality
Commission (CQC). The CQC tends to focus on
service issues, rather than individual complaints.
You can contact the CQC by letter, phone or on
their website. You may want to complain to
the CQC if you think a service is providing poor
quality care so they take this into account when
inspecting a service. Contact details:

www.cqc.org.uk/contact-us



More Information

More information about making an NHS complaint see the NHS Choices website:

www.nhs.uk/choiceinthenhs/ rightsandpledges/complaints/pages/ nhscomplaints.aspx

More information about litigation friends (SCIE)

www.scie.org.uk/publications/ quides/quide42/who.asp

If your family member lacks capacity and a decision is being made in their 'best interests', you have a right to be involved. Here is a tool to help challenge if you are not being involved (Irwin Mitchell)

www.irwinmitchell.com/activities/ best-interests-decisions-tool

What services are available to help my family member if they have experienced abuse and/or other sorts of trauma?

Your local Community Learning Disability Team (or other health or care professionals working with people with a learning disability in the community) should be able to advise if there is an appropriate service which would meet your family member's needs, and if so, make a referral. If more expert support is required, then you can ask for an expert from outside your area or a private therapist to be bought in.

Factsheet 2 has more information about the importance of the local authority involving relevant experts when your family member has a needs assessment or reassessment. This is an important opportunity for all your loved one's needs to identified, including any needs due to trauma they have experienced. Ask the local authority to involve professionals with expertise in trauma support for people with a learning disability if you think your family member may have experienced abuse and/or other sorts of trauma.

Organisations that may be able to help

Challenging Behaviour Foundation – a small national charity that specialises in supporting families who have a relative with severe learning disabilities and behaviour described as challenging. Offers individual support to families by telephone and email, a family carers' email network and a family linking scheme.

www.challengingbehaviour.org.uk

Citizens Advice Bureau – a charity that helps people resolve their legal, money and other problems by providing free, independent and confidential advice, and by influencing policymakers.

www.citizensadvice.org.uk/

Disability Law Service – charity providing free advice on community care law, disability discrimination, education, employment, welfare and benefits.

www.dls.org.uk

Hft - a national charity supporting people with learning disabilities and their families. Its Family Carer Support Service offers one-to-one support, workshops and publications for family carers supporting a relative with a learning disability, anywhere in England.

www.hft.org.uk/familycarersupport

Mencap – a UK learning disability charity that campaigns with people with a learning disability and their families for a better future, provides services and has a telephone advice and information service for anything related to learning disability.

www.mencap.org.uk

Mind – a mental health charity that provides advice and support to people experiencing a mental health problem, including an infoline and legal line, and that campaigns to improve services, raise awareness and promote understanding.

www.mind.org.uk

National Autistic Society – a UK charity for people on the autism spectrum and their families, providing information, support and services, and campaigning for a better world for people on the autism spectrum.

www.autism.org.uk

Respond – is a charity that works with children and adults with learning disabilities who have experienced abuse through psychotherapy, advocacy, campaigning and other support. They offer support to families through their family support service.

www.respond.org.uk

See Meeting the challenge:
Frequently asked questions about
the law written by Irwin Mitchell
Solicitors for more information
about your family member's legal
rights: www.irwinmitchell.com/
meetingthechallenge

Meeting The Challenge

Glossary

Safeguarding – means protecting a person's right to live in safety, free from abuse and neglect. The term 'adult safeguarding' is about those in need of care and support who may be at risk of abuse or neglect. The Care Act requires local authorities to make enquiries if it believes an adult is, or is at risk of, abuse or neglect.

Legal aid – Legal aid is funding that some people can get to help meet the costs of legal advice and representation in a court. A person's solicitor will apply for legal aid on their behalf.

Adult safeguarding team – a team within the local authority made up of dedicated practitioners who work on safeguarding issues, including receiving concerns about adults who have been abused or neglected or are at risk of abuse or neglect.

Community care solicitor – solicitors who specialise in community care law. Community care law is about the provision of health and social care services for children in need and for adults whose independence and wellbeing are at risk because of a disability, illness or age. A community care solicitor can provide support and assistance on a range of community care issues, such as assessments and support services for people with a disability. They can represent people in negotiations, formal complaints, ombudsman procedures and court proceedings.

Care Quality Commission (CQC) – the independent regulator of all health and social care services in England. The Care Quality Commission monitors, inspects and regulates services such as hospitals and care homes to make sure they meet fundamental standards of quality and safety.

Local Government Ombudsman – a service set up to investigate complaints about councils and some other authorities and organisations, including adult social care providers (e.g. care homes).

Parliamentary and Health Service Ombudsman

 a service set up to investigate complaints that individuals have been treated unfairly or have received poor service from government departments and other public organisations and the NHS in England.

Severe learning disabilities: Some people may have a mild or moderate learning disability; others may have a severe or profound learning disability. The level of support someone needs depends on individual factors, including the severity of their learning disability. People with a severe learning disability will need a significant amount of support with daily activities such as washing and dressing, and keeping safe. They are also more likely to have little or no speech.

For more information visit www.mencap.org.uk/meetingthechallenge

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