DOWN'S SYNDROME ASSOCIATION

Ensuring the rights and care of a family member with Down's syndrome in hospital

A quick reference guide for families

August 2024

Understanding and navigating the health and social care system can be particularly challenging when a family member is admitted to hospital.

Knowing your rights and the standards of care your family member should receive can therefore be important.

This guide delves into key legal protections, NHS responsibilities, the roles of healthcare professionals, and the processes related to mental capacity and best interest decisions, while also highlighting important resources and practical advice to help you advocate effectively wherever necessary.

Understanding your legal rights

Several important laws and guidelines protect the rights of individuals with learning disabilities at all times, ensuring they receive the necessary care and support.

Care Act 2014

Needs Assessment (Section 9):

Local authorities have a duty to conduct a needs assessment when it appears that an adult may require care and support. This is crucial during a hospital stay to ensure that your family member's needs are met, not just in the hospital but also during the transition back to the community or into a care facility.

Well-being Principle (Section 1):

The Care Act emphasizes the importance of promoting well-being, including the individual's physical and mental health, dignity, and protection from harm. This principle underpins all decisions made by local authorities regarding care and support.

Duty to Meet Needs (Section 18):

Once a needs assessment identifies care and support needs, the local authority must ensure these needs are met. Any delays or failures in providing necessary care could constitute a breach of this statutory duty. Ensuring that this duty is fulfilled is vital, especially when your family member is vulnerable and requires immediate attention.

United Nations Convention on the Rights of Persons with Disabilities (UN CRPD)

Article 25 – Right to Health:

The convention guarantees the right to the highest attainable standard of health, without discrimination based on disability. This includes ensuring that healthcare services are accessible, appropriate, and tailored to the individual's specific needs.



Human Rights Act 1998

Article 2 – Right to Life:

Hospitals have a legal obligation to protect the life of your family member. This includes providing timely and appropriate medical care, as well as taking necessary steps to prevent harm.

Article 3 – Right to Be Free from Inhuman or Degrading Treatment:

Any neglect, delays, or inappropriate treatment that causes suffering could potentially violate this right. It is critical that your family member is treated with dignity and that their care is not compromised.

Article 8 – Right to Respect for Private and Family Life

This includes the right to be involved in decisions about your family member's care. Throughout the hospital stay, you should expect to be consulted and informed about all aspects of their treatment and care planning.

The NHS Duty to Fund Additional Care

The NHS has a clear responsibility to ensure that individuals with learning disabilities receive the necessary care and support while they are hospital inpatients. This includes funding additional services if required to meet their specific needs.

NHS England Guidance on supporting patients with learning disabilities:

NHS England mandates that hospitals provide appropriate care for individuals with learning disabilities, which may involve making reasonable adjustments or funding additional support services. The goal is to ensure that all patients, regardless of their disabilities, receive fair and equal treatment that is tailored to their unique needs.

You can access the detailed NHS guidance on supporting patients with learning disabilities here.

Who pays for care in hospital?:

When a family member with learning disabilities is admitted to hospital, questions often arise about who is responsible for funding their care if additional help is needed in hospital. According to NHS England's guidelines, the NHS is generally responsible for funding care provided during a hospital stay. This includes any additional care required due to the patient's learning disabilities or related health conditions.

What to expect during a hospital stay

Understanding what you should expect when your family member is hospitalised can help you ensure they receive the best possible care. The NHS provides specific guidance on what individuals with learning disabilities and their families should expect during a hospital stay, which is crucial for planning and advocating for proper care.



Person-centered care

Care should be tailored to your family member's specific needs, considering their communication preferences, sensory sensitivities, and any additional support they might require. This person-centred approach is a core element of good practice and is supported by both the Care Act and NHS guidelines. It ensures that the care provided is not just clinically appropriate but also aligned with personal circumstances and preferences.

Timely and appropriate assessments:



Your family member should receive prompt assessments for any health conditions. NHS England guidance emphasizes that hospitals should conduct assessments and treatments without unnecessary delays, as timely intervention is crucial for maintaining health and preventing complications. This includes assessments for common health issues associated with Down's syndrome, such as cardiac and respiratory conditions.

Involvement in care decisions:

Both you and your family member should be involved in all decisions regarding their care. The Care Act statutory guidance stresses that care planning should be a collaborative process, with the views of the patient and their family central to decision-making. The NHS also supports this approach, ensuring that families are kept informed and involved in all aspects of their loved one's care.

Discharge planning:

Before discharging your family member, the hospital should ensure that all necessary care arrangements are in place. This includes coordinating with the local authority to ensure that appropriate support is available at home or in a care facility. The Care Act guidance requires that discharge planning ensures the individual's needs are met safely, and NHS guidance specifies that you should be fully informed and involved in planning the next steps. Discharge planning should be initiated early in the hospital stay to avoid any last-minute decisions that could compromise your family member's care.

Reasonable adjustments:

NHS England mandates that hospitals make reasonable adjustments to ensure that care is accessible and appropriate for individuals with learning disabilities. This includes offering longer appointments, providing information in accessible formats, or arranging for additional support during treatments. Ensuring that these adjustments are made is essential for safeguarding your family member's rights and well-being. For more detailed information on what to expect during a hospital stay, you can visit the NHS website.

Mental Capacity Act and best interest decisions

When a family member with Down's syndrome and learning disabilities is in hospital, it is crucial to understand the implications of the Mental Capacity Act 2005 and how best interest decisions are made. This Act provides a legal framework for making decisions on behalf of individuals who lack the mental capacity to make decisions themselves.

Mental Capacity Act 2005

The Mental Capacity Act applies to anyone aged 16 and over who may lack the capacity to make specific decisions for themselves due to conditions such as learning disabilities, dementia, or brain injuries. The Act presumes that an individual has capacity unless proven otherwise and sets out specific criteria for assessing capacity. If it is determined that your family member lacks capacity, any decisions made on their behalf must be in their best interests.

Best interest decisions

When making a best interest decision, healthcare professionals must consider all relevant factors, including the individual's past and present wishes, feelings, beliefs, and values. Family members should be consulted and involved in these decisions, as they often have the best understanding of what the individual would want. The decision-making process should be documented, and the reasons for the decision should be clear and transparent.



Role of Deputy or Lasting Power of Attorney (LPA):

If your family member lacks capacity and has appointed a Lasting Power of Attorney (LPA) or has a Deputy in place for health and welfare, the LPA/Deputy has the legal authority to make decisions on their behalf. If no LPA or Deputyship is in place, a Deputy may be appointed by the Court of Protection to make decisions in their best interests. Both the LPA and Deputy have a legal obligation to act in an individual's best interests and to consult with healthcare professionals and family members when making decisions.



Deprivation of Liberty Safeguards (DoLS)

If your family member needs to be deprived of their liberty in a hospital setting (for example for their safety or treatment), the hospital must apply for a DoLS, a safeguard designed to protect individuals who are deprived of their liberty in care settings. The DoLS process ensures that the deprivation is lawful, necessary, and in the person's best interests. You have the right to be involved in this process and to challenge the decision if you believe it is not in your family member's best interests.



Advocacy and the role of advocates

When navigating the complexities of hospital care, especially for individuals with learning disabilities, advocacy can play a crucial role. Advocates can help ensure that your family member's rights are protected and that their needs are met.

Independent advocacy

f you feel that your family member's needs are not being adequately addressed, you have the right to request an independent advocate. The Care Act 2014 mandates that local authorities must provide an advocate if an individual has substantial difficulty in being involved in care planning and has no other suitable person to support them. An independent advocate can help you navigate through the complex health and social care system, ensure that your family member's voice is heard, and also support you in challenging any decisions that do not meet their needs.

Advocacy Services and Legal Support:

Advocacy services can also help you understand your legal rights and provide support in taking any necessary legal action. In cases where your family member's rights are not being upheld, or if there is a serious failure in care, you may also need to seek legal advice. There are several examples where families have successfully challenged local authorities or healthcare providers over failures to provide adequate care via the Local Government and Social care Ombudsman. For example, in the Shropshire Council case (23 001 890), the Local Government and Social Care Ombudsman found fault with a council for delays in assessing an elderly woman's care needs and arranging appropriate support after her discharge from the hospital. The delay caused significant distress to both the woman and her family. The Ombudsman recommended the council apologize and make a financial payment to acknowledge the impact of the delays and distress caused, as well as to review its procedures to prevent recurrence.

Learning Disabilities Liaison Nurses

Learning Disabilities Liaison Nurses (LD Liaison Nurses) play a crucial role in hospitals, ensuring that patients with learning disabilities receive appropriate, person-centred care during their stay. These specialist nurses act as advocates for patients with learning disabilities, working to bridge the gap between the patient, their family, and the healthcare team.

Their responsibilities include ensuring that the patient's individual needs are met, such as by facilitating communication through accessible formats, adapting care environments to reduce anxiety, and ensuring that reasonable adjustments are made to accommodate the patient's specific requirements.

LD Liaison Nurses also provide support and education to other healthcare professionals, helping them understand the complexities of learning disabilities and how best to deliver effective care. This role is vital in promoting the well-being of patients with learning disabilities, reducing health inequalities, and ensuring that hospital care is safe, respectful, and tailored to the needs of each individual.

When entering the hospital, it is important to ask the admissions team or nursing staff about accessing a Learning Disabilities Liaison Nurse. Many hospitals have these nurses available, but they may not automatically be assigned unless requested. Families and carers should proactively inquire about this support when planning the hospital visit or upon arrival, ensuring that the nurse is involved in the patient's care from the outset. If the hospital does not have a dedicated LD Liaison Nurse, they may have other staff trained to support patients with learning disabilities or can provide information on accessing additional support.



What to do if things go wrong

Despite best efforts, there may be times when the care provided does not meet the required standards. Knowing what to do in these situations is vital to ensure your family member's well-being.

Raise concerns with the hospital:

If you believe that your family member's care is not meeting the expected standards, speak to the ward manager or another senior member of the hospital staff. Hospitals have a duty to respond to concerns promptly and take appropriate action to address any issues.

Contact the local authority

If the issue relates to care provision or discharge planning, contact your local authority's adult social care team. The Care Act requires local authorities to address any gaps in care and ensure that needs are met, both during the hospital stay and after discharge.

Seek legal advice

If necessary, seek legal advice to address any serious failures in care. Legal precedents highlight the importance of timely and adequate care assessments under the Care Act. You may also want to consider working with an independent advocate who can help you navigate the legal assistance, as they have expertise in the Care Act, human rights, and healthcare law.



Planning for post-hospital care

Effective planning for your family member's care after they leave the hospital is crucial to ensuring a smooth transition and continued well-being. This includes coordinating with both the hospital and local authorities to establish a comprehensive care plan.

Early discharge planning

The NHS and the Care Act both stress the importance of early discharge planning. The hospital should begin planning for your family member's discharge as soon as they are admitted to ensure that all necessary care arrangements are in place before they leave. This process should involve you and your family member, ensuring that their needs are fully considered and met.



Coordination with local authorities

The local authority's adult social care team should be involved in discharge planning, particularly if your family member will need ongoing support at home or in a care facility. The Care Act mandates that local authorities must ensure that any care and support needs identified in the hospital are met after discharge. This includes arranging for services such as home care, equipment, and adaptations, as well as ensuring that any required medical treatments continue seamlessly.

Accessing Continued Healthcare Support:

If your family member has complex health needs, they may be eligible for NHS Continuing Healthcare, which provides NHS funding for ongoing care. This could include care in their own home or in a care home. It is important to discuss this option with the hospital's discharge planning team to ensure that all funding and care arrangements are in place before discharge.

Follow-up care

After discharge, your family member should continue to receive follow-up care from the NHS and local authorities as required. This includes regular check-ups, ongoing assessments, and adjustments to their care plan as needed. The Care Act guidance emphasizes the importance of regular reviews to ensure that the care provided continues to meet the individual's needs.



Additional resources and support



Navigating the healthcare and social care systems can be challenging, but there are numerous resources and support services available to help you.

NHS England resources

NHS England offers a wealth of resources to help families understand their rights and what to expect when a family member with learning disabilities is in hospital. These resources include detailed guidance on hospital care, discharge planning, and accessing additional support services. You can find these resources here.

Local authority adult social care services

Your local authority's adult social care team can provide advice and support on accessing care services, including needs assessments, care planning, and funding options. They are also responsible for ensuring that your family member's care needs are met after they leave the hospital.

Independent advocacy services

If you need help navigating the healthcare system or advocating for your family member's rights, independent advocacy services can provide valuable support. These services can help you understand your rights, make informed decisions, and ensure that your family member receives the care and support they need.



Legal advice

If you encounter significant challenges in securing appropriate care for your family member, or if you believe their rights have been violated, it may be necessary to seek legal advice. Legal experts, such as Luke Clements or Belinda Schwehr, can help you navigate complex legal issues related to the Care Act, human rights, and healthcare law.

Making a complaint

A complaint letter to a Local Authority complaints team can be particularly helpful when there has been a failure in the provision of care or services, such as delays in discharge from the hospital due to the local authority not organizing a care package in a timely manner. Writing a complaint letter allows families to formally document their concerns and request specific actions to address the issues at hand. It serves as a clear, written record of the problem, which can be vital if the situation needs to be escalated to higher authorities, such as the Local Government and Social Care Ombudsman.

Additionally, a well-structured complaint letter can prompt the relevant parties to take immediate corrective action, ensuring that the needs of the patient are met without further delay. By outlining the impact of the service failure on the individual's well-being, the letter can also help in highlighting the urgency of the situation and the necessity for a swift resolution.



Useful web references

NHS England Learning Disabilities Guidance

Going into Hospital with a Learning Disability

Luke Clements' Website

Belinda Schwehr's Website

Appendix 1:

Template Complaint Letter: Delayed Discharge Due to Local Authority's Delay in Organising a Care Package

[Your Name]
[Your Address]
[City, Postal Code]
[Email Address]
[Phone Number]
[Date]
[Recipient's Name]
[Recipient's Title]
[Local Authority Name]
[Local Authority Address]
[City, Postal Code]

Dear [Recipient's Name],

Re: Formal Complaint Regarding Delayed Discharge of [Family Member's Name] Due to Delay in Organising Care Package

I am writing to formally raise a complaint regarding the unacceptable delay in the discharge of my [relationship, e.g., mother, father, brother, sister], [Family Member's Name], from [Hospital Name]. My [Family Member's Name] has been medically fit for discharge since [Date], yet remains in hospital due to the local authority's failure to organise an appropriate care package in a timely manner.

This delay is causing significant distress and negatively impacting [Family Member's Name]'s well-being. As you are aware, prolonged hospital stays for individuals with learning disabilities, such as [Family Member's Name], can lead to a deterioration in both physical and mental health. The NHS and local authorities have a duty to work collaboratively to prevent such delays and ensure that care packages are organised promptly to facilitate safe and timely discharges.

Summary of the situation

- Medically Fit for Discharge Since: [Date]
- Hospital: [Hospital Name]
- Consultant in Charge: [Consultant's Name, if known]
- Discharge Delayed Due to: Lack of an appropriate care package being organised by the local authority.
- Impact on [Family Member's Name]: [Describe any negative impacts on health, well-being, or mental state due to the delay in discharge, such as increased anxiety, physical decline, or any other specific concerns].

Legal framework and duties

Under the Care Act 2014, local authorities have a statutory duty to ensure that care and support needs are met in a timely manner. This includes the prompt organisation of care packages to prevent delayed discharges. The NHS England guidance on discharge planning also emphasizes the importance of avoiding unnecessary delays and the responsibility of local authorities to coordinate and implement care packages swiftly.

Additionally, the Human Rights Act 1998 mandates that public authorities, including local authorities, must act in a way that respects and protects the rights of individuals. In this context, the delay in discharge could be seen as a failure to respect [Family Member's Name]'s rights to private and family life under Article 8, as well as potentially infringing upon their right to be free from inhuman or degrading treatment under Article 3.

Requested actions

Given the above, I urgently request that the local authority:

1. Expedite the arrangement and implementation of a suitable care package for [Family Member's Name] to ensure their prompt and safe discharge from the hospital.
2. Provide a clear timeline for when the care package will be finalised and implemented.
3. Confirm the steps that will be taken to prevent such delays from occurring in the future.

If these actions are not taken promptly, I will have no choice but to escalate this complaint to the Local Government and Social Care Ombudsman, as well as consider seeking legal advice on potential breaches of the Care Act 2014 and the Human Rights Act 1998.

Conclusion

I trust that you will treat this matter with the urgency it requires and take immediate steps to resolve the situation. Please acknowledge receipt of this letter and provide a written response within [a reasonable timeframe, e.g., 7 days] outlining the actions that will be taken to ensure [Family Member's Name] is discharged safely and promptly.

Thank you for your prompt attention to this matter.

Yours sincerely,
[Your Name]
[Relationship to Family Member, e.g., Daughter, Son]

CONTACT US

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