healthwatch Sandwell

Case study: a patient's journey of moving to a care home

November 2022

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Case Study

This is a case study about a person* from the Black Country, an intelligent, grammar school educated, and articulate person who led a full life. They worked in a variety of settings and had travelled the world extensively. They enjoyed playing sports including cricket (professionally), football and golf. They lived alone in a 3rd floor flat in Sandwell and managed their own life including financial affairs as they had the mental capacity to make decisions about their own life.

In 2017, this person developed various symptoms including dropping cups etc. and after numerous hospital appointments and many consultations with Neurologists between 2017 and 2018, was diagnosed with a neurological disease. This neurological disease is a fatal condition that affects the brain and nerves, it causes weakness that get worse over time with no cure, it is slow and progressive. This person also has a hearing impairment.

They remained independent in their own home with a comprehensive support package from a domiciliary care company but grew weaker and had little or no use in their arms and legs. They can talk and move their head but uses assistive technology (iPad) to receive and send information.

In 2021 they deteriorated and was hospitalised for 2 weeks. A hospital social worker was allocated to assist with discharge, the person was discharged to a short-term placement at a nursing home in Sandwell (Enhanced Assessment Bed) while waiting to be assessed to go to a 90 Apartment Extra Care scheme in Sandwell which the person had been on a waiting list for extra care housing for 2 years. Unfortunately, after assessment, the person was declined a place for the extra care placement.

They were given a list of nursing care homes for them to choose from but was unable to visit due to poor mobility, a specialist nurse sourced a nursing home via a broker. Since the hospital admission the person has been nursed in bed, in a lot of pain and is confined to bed. They now live in a nursing home, out of borough, that was assessed as more suited to meet the person's needs.

* anonymised due to Healthwatch Sandwell privacy policy etc

Introduction

At first glance this case study and description of events sound relatively straight forward that is, a person with a progressive degenerative neurological disease > receives support at home > receives care in hospital > moves to a respite at care home > moves to a more suitable care home, however, this person's experience has highlighted many obstacles within the process and has been fraught with difficulties.

This paper will:

- Identify some of the challenges and obstacles that are faced by someone who has disabilities/impairments with regards to information received
- Offer key points to be considered based on the case study
- Make recommendations to Health and Social Care organisations for improvements
- Offer advice for care homes, Contract Monitoring Officers of care homes, Local Authority Quality Officer and Care Quality Commission

Background

This person contacted Healthwatch Sandwell (HWS) via the information email account in April 2022 querying if they had a 'right' to activities in a care home and how long these activities should be, including frequency, because they were having none at the time.

HWS advised appropriately based on assessment of need, ability, and preferences.

During conversations with this person the difficulties and challenges that they had faced moving to a care home became evident. This resulted in HWS signposting this person to *POhWER*[1] to be allocated an advocate who could assist the person in voicing their opinions to the right organisation. HWS also guided the person to various complaints procedures including Time2talk[2] to raise concerns about Continuing Healthcare funding. Some of these complaints are ongoing to date. HWS has continued to provide support to this person.

The HWS work programme for 2022/23 has an overarching theme of health inequalities. HWS have identified **3** areas of challenge and issues with accessibility for health care patients or individuals receiving social care support: language barriers, difficulties with use or access to digital technology and communication needs due to a disability, sensory loss or an impairment. This case study will contribute to the HWS work programme.

[1] a charity providing free advocacy, information and advice who help people who, because of disability, illness, social exclusion and other challenges, find it difficult to express their views or get the support they need.

[2] https://blackcountry.icb.nhs.uk/get-involved/time-2-talk

Conversations with the person identified the following **5** themes that this person had encountered, this section will identify the theme and pose questions to be considered:

1. Moving to a care home – accessible information to make a choice

People who have various neurological diseases[3] live independently in their own home with support, but there are times when remaining independent is no longer viable and the only option is to enter a suitable residential/nursing care home.

Some people with a neurological disease may have the capacity[4] to make decisions for themselves but due to their physical impairments may need support to access information and to visit care providers to help make this important decision.

People need accessible information about what's available that is suitable to meet their needs so they can make an informed choice. Accessible information is information which can be read, received, and understood by the individual.

A person moving to a care home needs to understand the process of moving, i.e. assessment of need, care plan, contract and funding etc.

The Accessible Information Standard (AIS) was introduced by the Government in 2016 to ensure that people with a disability (including learning disability) or sensory loss are given information in a way they can understand. It is the law for NHS and Adult Social Care Services to comply with AIS. See appendix one for requirements on NHS and Adult Social Care Services.

In late 2021[5] a coalition of charities surveyed NHS and social care professionals in England, as well as disabled people who have accessible information and communication needs, about the AIS. After five years of the Accessible Information Standard, the survey found:

11% of patients covered by the AIS have equitable access to the NHS.
81% of patients reported having an appointment when their communication needs were unmet.
77% of people with accessible information needs reported rarely or never receiving information in alternative formats.

[3] Neurological diseases include Alzheimer's disease, Cerebral palsy, Epilepsy, Motor neurone disease, Multiple sclerosis, Parkinson's disease etc.

[4] https://www.nhs.uk/conditions/consent-to-treatment/)

[5] https://signhealth.org.uk/resources/research/review-of-the-nhs-accessible-information-standard/

Only **41%** of complaints procedures were reported to be accessible by the professionals who filled in the survey.

This is extremely disappointing and unacceptable.
This person uses technology proficiently and relied upon information technology to communicate and to gain information. This person found that some websites were not up to date which hindered decision making.

When a person is allocated a Local Authority social worker/adult practitioner, the practice in Sandwell is to give a person a list or hyperlinks of all providers, which may include Providers that may be in special measures and those that are not taking new residents (due to block contract).

This person was given a list of approximately 9 care homes, to choose from, but the majority of them were further away from family so were unacceptable. The list needed to be relevant to the persons wishes.
This choice should apply to respite care homes, if the Local authority has a block contract[6] for respite beds, then the choice may be limited, but this needs to be communicated to the person. This was not the case.

HWS acknowledge that Local Authority social worker/adult practitioners cannot recommend a placement but the information provided needs to be relevant, up to date and accessible for a person with limited physical ability and sensory impairments.

The Care Act 2014 places a duty on local authorities to make sure that:

- the person participates as fully as possible in decisions and is given the information and support necessary to enable them to participate
- decisions are made having regard to all the individual's circumstances (and are not based only on the individual's age or appearance or other condition or behaviour)
- any restriction on the individual's rights or freedom of action is kept to the minimum necessary for achieving the purpose.

Section 4 of the Care Act 2014 covers:

- The duty placed on local authorities to establish and maintain information and advice services relating to care and support for all people in its area
- The broad audience for the information and advice service
- The local authority role with respect to financial information and advice
- The accessibility and proportionality of information and advice
- The development of plans/strategies to meet local needs

[6] A block contract is a payment made to a provider to deliver a specific, e.g. rehabilitation care beds.

Sandwell MBC need to ensure that they adhere to the Care Act 2014 so that they are meeting their statutory responsibilities.

Key points to consider:

- How can a person make an informed choice and also be at the centre of the decision making about their life when they do not have accessible information about the process of moving to a care home and the related issues?
- Communication with people who have capacity and may have sensory impairments needs to be clear and understandable, especially when face masks are being used (Covid-19 precautions)
- Are care home websites up to date?
- Is written information accurate and up to date, including lists of care homes?
- How can a person with a physical disability visit a care home to make an informed choice?
- How do Local Authorities fulfil their duties under The Care Act 2014 e.g. the person participates as fully as possible in decisions and is given the information and support necessary to enable them to participate and to make an informed choice.
- Is it legal if a resident isn't given a choice of care homes?
- Explain the process of going into a care home.
- How do the NHS and Adult Social Care Services comply with AIS legislation?

2. Role of support staff

Traditionally a social worker would be allocated to a vulnerable person requiring assistance, this may be the only source of support, and would be relied upon to provide information both financial and availability of placements as well as a review of the placement to ensure that the placement is suitable.

This person was allocated a social worker to assess care needs and assist with the move to an appropriate care provider. The person was unclear what the social workers role was and what they could expect. A review was executed via email asking if the person was 'happy'.

A Personal Assistant would have been useful to oversee the move, including visit care providers as well as deal with finances, informing utilities, credit cards and Department for Work and Pensions etc. of the move, especially when there is no family or unable to do so for themselves.

The person assumed that the Social worker would undertake these duties, but they did not.

There are a variety of support systems available, e.g. broker, a broker supports people of various disabilities and health conditions and long term illnesses. However, there is a cost and has to be sourced by the service user.

This person was guided to a broker by the specialist nurse.

Key points to consider:

- Make clear the role of a social worker to the service user[7]
- Access to a Personal Assistant / broker ?
- Who informs the utilities and DWP about the move ?
- A comprehensive review of placement to take place with a new resident

3. Financial issues

The funding of residential/care home can be a complex matter, especially if your income and capital are over £23,250 (correct at time of writing October 2022) and whether your needs are healthcare and/or social care based.

It is daunting and stressful to make the decision to move in the first instance, complex financial uncertainty exacerbates this. An average person would **not** have an understanding of this process, it is not until a person requires this option that they would become aware of the complexities.

As stated, the funding is complex, funding for health care needs require a Continuing Healthcare assessment (CHC)[8]. The social worker refers for a full CHC assessment to the local Integrated Board who co-ordinates the assessment. This assessment determines eligibility, if the assessment deems the person to be ineligible then there is an appeal process.

Funding for social care is assessed by a Social worker (Adult Social Care).

This person had lots of unanswered questions with regards to the financial assessment for care, this was complicated by Personal Independence Payment, care needs assessments and means testing etc.

There was also a lack of understanding about CHC eligibility criteria and the appeal process.

[7] https://www.basw.co.uk/resources/become-social-worker/what-do-social-workers-do

[8] https://www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/nhs-continuing-healthcare/

The person did not receive confirmation of fees in writing from statutory organisations.

As this report has already stated there is a need for accessible financial information, Section 4 of the Care Act 2014 highlights the local authority role with respect to financial information and advice.

Key points to consider:

- Provide accessible financial information to a prospective care home resident
- Explanation of CHC process including how to appeal

4. Contract at Care Home

When a person enters a care home they should be given a contract, which is signed by the resident. There are a variety of scenarios which require different contracts:

- Self-funding residents: the contract will be between the resident and the care home.

- Residents who the Local-authority pay: the contract will be between the local authority and the care home. In this situation, the person should be given a copy of the contract

- Shared payment: If the local authority is part-funding the care but someone else is paying a top-up fee to the care home, there will be two contracts – one between the local authority and the care home, and another between whoever is paying the top-up fee and the local authority.

The contract should cover a variety of things including the level of care and support, what will happen if care needs change. The contract should be given in an accessible format to the person especially as they have capacity to consent **not** to third party or next of kin.

This person has not had a contract to date either from respite care or nursing home, so does not know their rights and responsibilities, neither was it signed.
The person has a support plan, completed by the social worker, but the funding of care was vague and inconclusive.

Key points to consider:

- Be given a contract to include all the information a new resident including final responsibility would need in an accessible format
- Is it legal/binding if the contract isn't signed by the resident

5. Care at respite home/ nursing home

Care Planning

Care given at a care home is based upon an assessment of holistic needs[9], whereby the person is at the centre of the assessment and is encouraged to voice their wishes, needs and wants. This assessment is recorded in a care plan and regularly reviewed.

The Care Act 2014 (Section 24) describes the Care and Support Plan which is required when people are having their needs assessed, this is usually completed by the social worker. However, once a person enters a care home, the home will provide a care plan (or support plan) which will be in formed by the social worker's Care and Support Plan, it should be written in collaboration with the resident as they are best placed to know what they need.

The homes care plan will include simple assistance with day-to-day tasks and support taking medication, all the way to round-the-clock supervision and ongoing medical and social care. It is essential that residents' physical needs are identified and met to include finger and toe nail cutting, washing, dressing, appropriate medication and access to primary care: GP, optician, audiology etc.
It should also identify potential hazards and risks, including any specialist equipment e.g. bed rails.
The care plan should also identify arrangements for access to finance.

This person had difficulty accessing all the above.

This person had experience of medical symptoms not being addressed with the appropriate medical person which then resulted in a skin condition being undiagnosed until sometime later by a dermatologist.

This person did not know what they could expect and what they were required to pay for.

These care plans and associated daily records need to be accurate and true. Residents need to have an accessible up to date copy to verify facts that has been agreed with the resident.

This person did not have access to the home's care plan and daily records.

Principles of care

Care should be given in adherence with the principles of care as identified by Social Care Institute for Excellence[10], these include choice, dignity, independence, partnership, privacy, respect, rights, safety, equality and inclusion, and confidentiality.

[9] A Theory of Human Motivation, by American psychologist Abraham Maslow (1943)
[10] https://www.scie.org.uk/person-centred-care

This person did not have care given using these principles.

It is essential that Institutionalisation in care is avoided, this is a type of residential care for large groups of people. It is characterised by a one-size-fits-all approach according to which the same service is provided to all people irrespective of their age, gender, abilities and needs. Institutional abuse occurs when the routines, systems and regimes of an institution result in poor or inadequate standards of care and poor practice which affects the whole setting and denies, restricts or curtails the dignity, privacy, choice, independence or fulfilment of adults at risk' (SCIE 2010)[11].

This person described his daily routine, which had very little social interaction and his daily routines could be described as institutional, the resident stated that:

'I'm lucky if I get my pad changed three times a day'

Comments and Complaints

The culture of the home should welcome feedback and constructive criticism. If a resident isn't happy then communication should be open and honest, without fear of repercussions and guided to the complaints procedure. It should be made clear to the resident who to raise concerns/compliments with.

The Social worker advised this person to complain to the CQC who do not address individual resident's complaints.

I'm not giving up I'm a fighter…that's what we do… we don't complain…is stops them doing their job'

Staff Training

Staff should receive appropriate training to meet the needs of the resident which uphold these principles.

This person gave examples of inadequate care including:

- **Vaseline being applied like eye shadow to remove matter from eyes, instead of a damp cotton pad.**

[11] https://www.scie.org.uk/publications/guides/guide46/commonissues/institutionalisedcare.asp

- **Not having access to an appropriate emergency buzzer which resulted in the person having to phone carers (from own mobile phone) in an emergency to summon help.**

Points to consider:

- A care plan (or support plan) to be devised which include all residents needs and involve the resident in decision making holistic needs of the resident
- Are daily records kept that are accessible to the resident?
- Do staff receive training in giving effective and safe care?
- Is staff performance managed?
- Is care non institutionalised to avoid abuse?
- What is the culture of the home with regards to complaints?
- Are placements reviewed to ensure they are appropriate?
- What is in place if a resident wants to view other homes or move ?

Conclusion

Moving to a care home is not an easy decision to make, this case study has given a picture of a person's experience, who has a neurological disease, of moving from their own home to a care home. The move was fraught with difficulties.

This paper has identified some of the challenges and obstacles that are faced for someone who has disabilities/impairments with regards to information. It has also given points to be considered throughout the paper.

It is essential that people have accessible information both verbal, written and including websites to comply with The Care Act 2014 and the Accessible Information Standard (2016). This should include information about fees, care and complaints procedures etc, to make ensure that they can make informed choices.

New residents need to be able to visit a home (s) to ensure they have a choice and have access to appropriate staff to support the transition.

New residents to be given a comprehensive care plan and contract. Care should be given by staff who are well trained and managed so that there is an open culture with non-institutionalised care to avoid abuse and that care is safe and effective.

Recommendations

From the findings HWS make the following recommendations for Health and Social Care organisations including care homes, Contract Monitoring Officers of care homes, Local Authority Quality Officer and Care Quality Commission:

1. Health and Social Care providers to make all information accessible to meet the needs of anyone with a sensory impairment and a disability who require health and social care.
2. Adult Social Care (Sandwell MBC) to ensure that they adhere to the Care Act 2014 so that statutory responsibilities are met.
3. Ensure that appropriate support staff assist with the transition to care home, either from Adult Social Care or care home.
4. Care homes to ensure that all new residents have a comprehensive care plan that is regularly reviewed and is drawn up with the resident.
5. Training for social workers, support workers and care home staff to meet national guidelines.

Acknowledgements

HWS would like to take this opportunity to thank the person* who shared their experiences.

Disclaimer

All data provided in this report was accurate at the time of the project.

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Appendix

Appendix one

Accessible Information Standard (2016)

Requirements on NHS and Adult Social Care Services:

1. Find out communication and information needs
2. Record these communication and information needs clearly and consistently on records
3. Flag these needs, so when a member of staff opens the records it is really clear what the communication or information needs are
4. Share the information and communication needs when required, for example if they are referring to another service.
5. Take action to give the right support. For example, offering easy read information or making sure there is someone there to support you with communication e.g. British Sign Language interpreter.

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