Gloucestershire
Safeguarding Adults
Board

Gloucestershire Safeguarding Adults Board: 7-Minute Learning Brief

Who was Mr A?

Mr A had a neurodegenerative disease which had been diagnosed a decade before. Now in his 50s, Mr A was estranged from his family and was very isolated. He had stopped attending health appointments and was neglecting his own nutrition, environmental and health needs. Practitioners found it hard to engage with him, although he did have a trusting relationship with a health team and with the Gloucestershire County Council enablement team. The enablement team worked with him for several months, making a significant difference to Mr A's independence and quality of life. Significantly, the enablement practitioner could support Mr A's connections with other services and volunteers.

Mr A had no assessment of his care and support needs since 2015 when these were assessed as 'substantial'. Mr A's neurodegenerative disease continued to progress. Undertaking an assessment under section 9 or section 11 of the Care Act (2014) would have explored Mr A's difficulties in identifying and problem solving around his own needs and the potential for a statutory advocate to support him through this process, ensuring that rights were met, and legal duties were followed.

The impact of the disease on his executive function meant that Mr A sometimes lacked the ability to think, act, and solve the problems of everyday life. Mr A's capacity was not assessed, and his struggles with executive function not appreciated.

Although fire risk was identified in Mr A's dwelling no referral for a Fire and Rescue Service Safe and Well check was made for several months.

After a period in hospital two friends offered to give care and support to Mr A, this was his preference and noted at a discharge planning meeting. This endeavour was far more than they appreciated and for various reasons their care fell short of what Mr A needed. There were also concerns that he was being financially abused by one friend.

Safeguarding responses by the local authority did not take account of Mr A's basic needs but were focused on the actions of the third parties involved.

Mr A's body was found by a support worker who had called in to deliver food. He died after choking on food. He had not been seen by any service for eight days and support from friends at this point was unknown and likely to have been inconsistent.

Key Learning from the SAR

1. **Good practices** identified in the SAR included how support and enablement practitioners engaged with Mr A. This process took time and tenacity but resulted in a trusting relationship. Starting with a brief conversation at the door, practitioners continued to attend Mr A's address and slowly progressed through the front door to the hallway and then through to Mr A's living room. Practitioners appreciated and valued Mr A's unique perspective on his life, he understood this.

What can I do? Think through how you will engage and form a relationship with a person. People value:

- Practitioners who understand and value their perspectives and views and who are good listeners.
- Having personal uniqueness valued, not being pushed into a theoretical explanation.
- Involvement that is purposeful and supportive.
- Being asked to define problems and goals - leading to a mutual understanding.
- Practitioners who adopt a 'friendly' approach, showing warmth, empathy and genuineness.
- Practitioners who demonstrate respect, honesty and reliability. *Ruth Ingram 2013.*[1]

2. **Reasonable adjustments**. Organisations will need to make 'reasonable adjustments' to existing policies and procedures in order to work effectively with people who have neurodegenerative diseases. Practitioners must understand the impact of the disease on how the person can engage and follow through on agreed actions. A shared and personalised care plan can be used to engage with individuals and include details of who can facilitate engagement.

What can I do? Think about the impact of the person's disease and circumstances. What reasonable adjustments are needed? How do they prefer to communicate? Who do they already know or trust – there may be someone who can help you to engage. Remember to share a person's reasonable adjustments with others, with the person's consent and support you can create an engagement plan for use in different situations.

3. **Access to expertise**. Each organisation needs to have access to expertise about neurodegenerative diseases. This could be through contacting the associations set up for a specific disease and/or can be through a colleague who has developed expertise in neurodegenerative diseases and can share this with others.

What can I do? When working with a person with a neurodegenerative disease find out more before you meet with them. It is exhausting telling new practitioners the same information. Is there an association you can contact to get more information? Is there

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[1] Ingram, R (2013)'Locating Emotional Intelligence at the Heart of Social Work Practice' British Journal of Social Work, 43(5):987-1004.

someone in your organisation who has worked with people with the same condition and can advise you?

Have you worked with someone with a neurodegenerative disease? Are you interested in finding out more and advising others? Speak to your manager for more information about training and support to become a colleague advisor.

4. **The importance of enablement**. People with a neurodegenerative disease who are isolated will need an enabler to support their engagement and use of services. They cannot achieve this without consistent, trusted support. Enabling or supporting such a person can be intense, good support and supervision is essential, from the practitioner's own service and from specialist services.

What can I do? Consider enablement support if the person is isolated and un-befriended. Ensure that the enabler has access to planned support and supervision. If you are the enabler, consider how you will be supported, the role is demanding and requires regular structured and planned support.

5. **Self-neglect**: Engaging with a practitioner or service does not mean that the risks from self-neglect have been removed. Risks should be identified and re-evaluated with the person and other involved services regularly.

What can I do? Do not assume any risks arising from self-neglect have diminished simply because the person has accepted support from one organisation. If you are concerned do raise the issue, either with the involved organisation, via a multi-agency meeting or by making a safeguarding concern referral.

6. **Risk assessment in adult safeguarding**: Risk assessment is supported by the use of professional curiosity, in particular the concept of 'safe uncertainty'.

   What is 'safe uncertainty?' What is happening, what the risks are, and what could help are usually uncertain in adult safeguarding. We need to be open to that uncertainty, to consider all information with an open mind, continually testing our own and others' assumptions. Whilst we are doing this, we must also keep a focus on a person's basic needs – Are they eating? Warm? Getting urgent medical help? Ensuring that the person's basic needs are met must be a priority whilst exploring other concerns within a referral.

7. **Fire Risk.** All services who enter the dwelling of a person with care and support needs have a responsibility to recognise fire risk and refer for a Safe and Well check. A house fire is unusual, but often fatal for people who have a combination of vulnerabilities.

What can I do? Think, do you know how to recognise fire risk? Do you know how to refer for a Safe and Well check? Find out here https://www.gloucestershire.gov.uk/glosfire/your-safety/safe-and-well/

8. We need to understand and use the law.

We must respect a person’s self-determination and balance this with our duty of care. However, we need to find ways forward to enact our legal duties and duty of care when our professional knowledge tells us that the outcome of self-determination may be detrimental to the person’s wellbeing.

A person may decline an assessment of care and support needs (Care Act 2014 section 9), but 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[2] points out 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.”

We cannot always assume mental capacity when a person has a neurodegenerative disease. It is important to get advice from specialists on the potential impact of the disease on capacitated decision making and the support that will be needed to enable the person to make their own decision. Observation and relationship building can help us identify whether there are issues of executive functioning.

What can I do? Do not ignore legal issues that appear tricky or try to displace them onto other organisations. If unsure ask for advice. Check – in your organisation who will help you resolve uncertainty about the law?

9. Working together:

A lead agency to coordinate other services is essential in situations of complex need. Whether the lead agency for coordinating care is from a health or social care organisation the emphasis must be on sharing responsibility and clear communication. The probability of creative solutions to concerning issues increases if all involved meet regularly.

What can I do? When convening multi-agency meetings ask each service attending – Who else is involved with this person? If you are an attendee, look down the invitation list – is there anyone missing?

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[2] https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice Page 25.