

Event summary

In the months leading up to Margaret's death, there was a marked **increase in involvement** of multiple health services. From that time Margaret's family's increasing concerns led to multiple **attempts to coordinate assistance** from **health and social care** providers.

The care provided to Margaret was **fragmented** and a **care needs assessment** was not undertaken. Margaret's **reluctance to accept** stronger pain relief, support, and medical interventions also compounded the challenges.

Margaret's **mobility declined**, she became **incontinent** and for a period towards the end of her life she was **housebound** and living on her sofa.

Ultimately Margaret **died in pain** with **no palliative care** or Treatment Escalation Plan (TEP).

Key learning & improvements

There was an absence of **professional curiosity**, no evidence of assessment of the **home environment** or Margaret's ability to adequately meet her **basic needs**.

Care was often **reactive**, and frontline staff often **focused on completing specific tasks** (e.g. taking blood tests, checking equipment) without broader assessment of Margaret's living environment or overall well-being.

There was no **Treatment Escalation Plan (TEP)** in place, leaving care providers without clear guidance on Margaret's preferences, and making **decisions on her behalf** during her end-of-life stage.

This key intervention, along with advanced care planning, had not been initiated at a time of **increasing vulnerability** and declining health.

Telephone assessments were not always appropriate; **home visits** would have been crucial to better understand Margaret's situation. There was a tendency to accept Margaret's statement of **"I'm fine"** at face value without probing further.

There were **missed opportunities** for health and care providers to make Margaret more comfortable in the last few weeks of her life. **Earlier honest conversations** with the family about the likely trajectory of illness could have shifted focus towards **comfort and quality of life**.

There was **unclear communication** between the family, providers, and social care regarding care planning. Margaret's **family faced overwhelming responsibility** in navigating the healthcare system, including arranging transport, advocating for care, and addressing gaps left by service providers. There was **no coordinated approach** in signposting as to how and where support could be obtained, or understanding of what was available and could be accessed.

Pre-arranged **hospital transport was cancelled** day-of, frustrating the family and causing Margaret to miss her gynaecology appointment. This created a **missed opportunity for cancer diagnosis** and potential Continuing Healthcare Fast Track funding for care at home.

However, discussion at the learning review considered whether this 2-week-wait referral for an outpatient's appointment was appropriate given Margaret's condition, and whether a **more holistic approach** would have been to initiate a **palliative care pathway**.

The family were informed that they would need to **self-fund** Margaret's care, but **no information was provided** regarding any **alternative health-funded services** she may have been eligible to receive.

A **care needs assessment should have been initiated** earlier, particularly after paramedics visited Margaret in April. In November, the family were **informed that she didn't need a care needs assessment** due to her self-funding status, however Margaret was still entitled to one.

The family would also have been eligible for a **carer's needs assessment**.

Professionals were not always able to **distinguish between self-neglect and self-determination**, especially when capacity was intact.

It was also too easy to **assume capacity**. Related concerns, considerations, and decisions were **not consistently documented** or followed through.

Clearer, standardised pathways for **interagency communication** and referrals need to be developed.

Shared access to e-records could improve this.

Professionals need stronger **awareness of available local resources** and how to navigate them efficiently.

Families also need more **structured support** and guidance on how to navigate health and social care services, including easily **accessible information** and contact points.

Local **directories**, Locum **packs**, and **patient-facing materials** could help with this.

The non-emergency patient transport **booking process should be simplified** and the accompanying **risk assessment protocols strengthened**. To ensure that transport is appropriately booked to meet the needs of the patient, and the crew is able to complete transfers as planned.

Advanced care planning needs to be **introduced earlier** for patients who are showing signs of **frailty** or **terminal** conditions.

TEPs should be initiated and communicated effectively, and **considered proactively** instead of during crisis. GPs and care coordinators should be more involved in initiating these discussions.

District Nursing **Health Care Assistants and Phlebotomists** should be **empowered** to consider a patient's **overall well-being** and **living environment** when attending a patient's home to i.e. take bloods, and be able to flag any observational concerns.

Structured risk assessments and/or **checklists** could support this.

Identified successes

The **family was actively involved** in Margaret's care, acted as her advocate and demonstrated resilience in seeking support, which provided vital insights for reflection.

Paramedics demonstrated excellent **responsiveness and compassion**, notably flagging safeguarding concerns, and making **reasonable decisions** for Margaret in the absence of a TEP.

A **digital automated function** within the Paramedics' form ensured a **prompt referral** was sent to the Rapid Response Service after an ambulance attended.

Despite being in a challenged position, the GP surgery **fulfilled every request** made by a professional for Margaret to have an appointment.

Margaret's independence and **wishes were respected** throughout, though this occasionally led to delayed care.

This review included **attendance and/or information** from:

- General Practice
- District Nurses
- Rapid Response Service
- Community Rehabilitation Service
- Ambulance Service
- Non-Emergency Patient Transport Service
- Domiciliary Care Provider
- Adult Social Care
- NHS Somerset ICB
- and Margaret's family

Do share wider with teams within your organisation and help disseminate the learning into practice

