

# Case Study

**If something doesn't feel right,  
speak up. Don't put it off.**

**Lucy's story of dealing with the concerns she had  
following the death of her mum.**

Lucy has agreed to share her experience, as she does not want others to be in the same position she was, experiencing the feeling of being powerless and unable to help a parent or loved one.

## Lucy's mum - Anna

Lucy's mum (Anna) lived on her own and was very independent, she was being treated by her local district nursing team for wound care following a fall. Anna had regular wound care visits to dress specific areas of skin on her legs.

With a decline in her mobility, Anna effectively became housebound and was attended by the local occupational health team to help her cope at home. Despite this her mobility declined rapidly and she became increasingly frail. Struggling to get into her bed she spent all day in her recliner chair and slept in it at night.

**Anna was developing pressure sores so during one visit by the district nursing team she finally consented to having a hospital bed delivered to her home. But Anna was unable to get in and out of the bed and was still sleeping in the chair. Despite telling the district nursing team this, a few weeks later they reported the pressure damage was improving.**

Around the same time Anna's housekeeper noticed a smell in the house which did not seem to go despite thoroughly cleaning the house and even bleaching the drains.

Lucy noticed her mum was becoming confused by all the interventions from various NHS professionals coming into her home. But Anna was adamant that she was being looked after, and with some rest she would be on the mend very soon.

Soon afterwards Anna had another fall. The ambulance service attended but did not take her to hospital. Lucy was becoming very worried now and attempted to speak to the GP to raise her concerns. The GP would only speak to Lucy if her mum signed a consent form.

Meanwhile Anna had another fall and was taken into her local acute hospital, and it was only then that Lucy then became aware of the full extent of her mum's condition. Her kidneys were failing, and the pressure sores had become necrotic, she was borderline septic.

### **The smell in Anna's house was necrosis.**

Necrosis, as defined by the NHS, refers to the death of cells or tissues in the body. It can be caused by various factors, including injuries, infections, diseases, lack of blood flow, or extreme environmental conditions. The affected tissue may appear brown or black and can be soft or hard, potentially with an unpleasant smell.

**Anna was made comfortable in the hospital but sadly passed away two weeks later. Following her mum's death the GP emailed Lucy to ask how her mum was, further compounding Lucy's belief that the various teams involved in her mum's care were not communicating effectively.**

Lucy requested a meeting with the GP and practice manager to find out what could be learned from Anna's experience. On arrival she was asked to sign a non-disclosure agreement which she declined. For her this was another sign that admin and box ticking has become more of a priority than caring for people.

# Independent Health Complaints Advocacy Service

Lucy approached her local independent **health complaints advocacy service** as she wanted to raise her concerns that her mum had been suffering in the weeks and months leading up to her death. Lucy understood that her mum was frail and was going to pass away, but she felt the fear and pain that she experienced during this time was unnecessary and avoidable.

**She did not want anyone else's loved ones to go through this.**

Lucy received her complaint response letters, and the GP Practice stood firm, they did not have consent to share any information with her. The district nursing team complaint response considered the damage on Anna's heel was due to a long lie following her fall before she was admitted to hospital. They did confirm that no formal falls assessment had been completed and because of Lucy's complaint the Trust agreed to review the falls risk assessment process to ensure robust assessments are completed for patients without any delay in future.

**They confirmed there had been poor communication between teams involved in Lucy's care, and the Trust have since been introducing multidisciplinary team meetings (MDT) to ensure a more co-ordinated and proactive approach to care and better documentation for all actions taken.**

The Trust accept the odour of the wound should have been considered as part of the wound assessment. Finally, the Trust confirmed that it is beneficial to involve family members in discussions regarding care and support needs, however as Anna was deemed to have the mental capacity to make her own decisions and was able to request the referral without support from her family member, contact with the family was not considered necessary.

## Apply for consent to speak on behalf of your parents or loved ones.

Lucy would like to encourage you to consider that if you need to apply for consent to speak on behalf of your parents or loved ones, don't put it off and be left in the position she found herself in. Trust your gut and don't assume your loved one is in control of the situation. Pride, fear or confusion might be standing in the way of them asking for help. If something isn't adding up, don't hesitate to get involved.

Approach the GP practice to confirm how to apply for consent, most GP practices require a written signed letter confirming who you consent to share the information with and if you can speak on their behalf. You can also apply for **Lasting Power of Attorney (LPA)** for health and wellbeing, and this can be put in place but only becomes active when the person loses the capacity to make decisions themselves.



## Feedback from Lucy

Dear Advocate

It would not have been possible for me to find my way through the maze without you. Your work is so important, and I appreciate everything you do. Thank you so much for your support kindness and wisdom.

Lucy (& Anna) x♥x

## Advocates reflection

It was a pleasure to support Lucy with her NHS complaint and helping to deal with the concerns she had following the death of her mum; the process has helped her to grieve.

I would also like to share that I have been in Lucy's position, a few years ago, a family member needed urgent treatment, I too could not speak to the GP. Becoming desperate, I asked the receptionist at the GP Practice to listen to my concerns, I was advised to call an ambulance, which my family member refused. Finally, later in the day the doctor did call and requested attendance at the surgery. The GP could see the urgency and advised attending A&E asap.

As a result of this incident, I now have consent to speak to the GP about concerns I have relating to my family member's health.

I too would encourage you to think about what is best for you and your loved ones, do you need consent, don't leave it too late, action beforehand will not leave you in the position Lucy and I found ourselves in.