Testimony to NI Assembly Health Committee Inquiry into Palliative Care 12 June 2025

1) Anne Sheppard - The Person

- Wonderfully wife, mother, grandmother & loyal friend to many people.
- Trained as an Occupational Therapist in Edinburgh (1970 – 1973) but returned to work in N. Ireland (1973 – 1992): Elderly (BCH, Belfast & Braid Valley, Ballymena); Community (E. Belfast & Castlereagh); Children with physical disabilities (Fleming Fulton, Belfast & Beechgrove, Ballymena schools).
- Woman of immense talent in a wide variety of crafts. Active member of the local Women's Institute. Volunteered with Active Listening & Healing on the Streets. Co-leader of Grief Share courses for several years.

2) Anne's Cancer Journey

- Diagnosed with *Chronic Lymphocytic Leukaemia* (CLL) in 2010. 'Watchful waiting' under NHSST consultant haematologist for the next 12 years at Laurel House (Antrim Area Hospital - AAH). A cytokine storm in her last few months necessitated blood transfusions & Zolendronic infusions.
- March 2020 (Covid19) lockdown. Extremely strict shielding! Key avoid having to go hospital (due to her compromised immune system) at all costs. But July 2020 discovered a *breast lump which proved to be cancer* (stage 3/ grade 3 and had spread into lymph nodes). Surgery (AAH, August 2020) – chemotherapy (Laurel House AAH, October 2020 – January 2021) – radiotherapy (Cancer Centre BCH, February – March 2021). Daily Medication for the next 2 years (Ibandronic Acid).

  N.B. Anne did all on her own as we were not allowed to accompany her due to hospital covid restrictions.
- Autumn 2022, Anne developed a persistent unproductive cough. Treated as a cold – pneumonia – pneumothorax over the next 3 months. At Antrim Emergency Department (ED) 1 February 2023 CT scan showed *mass on Anne's liver* which triple-phase liver scan on 2 March confirmed.
- Series of various diagnostic scans, biopsies etc. over next 2-3 months and referral to gastroenterologist.

- 2 June 2023 finally confirmed Anne had cancer of liver & pancreas (Cholangiocarcinoma). She was too weak for any chemotherapy treatment etc. except palliative care.
- Anne died at home on 18 July 2023 with close family by her side.

3) Care and treatment – what went well!

- *NI Hospice Specialist Nurse* – "worth her weight in gold." Her knowledge, experience & advice were absolutely invaluable. She physically examined Anne regularly & was able to provide solutions to Anne's many & developing symptoms (including infections) as her health rapidly deteriorated. She briefed us as family/ carers what could happen next & what to do. This helped take much of the fear & panic out of situations we were to face. She directed us to some much-needed practical help through Macmillan Cancer Care (Blue Badge; Attendance Allowance etc.). Her holistic approach (physically, emotional & spiritual) meant Anne felt she was seen and heard as a person and not just a case. We cannot overemphasise how deeply Anne valued this.
- *Northern Health Social Care Trust (NHSCT) Homecare Team* – wonderful team of ladies who washed and dressed Anne in her final weeks of life when she was physically too weak to look after her personal care needs. They did it with immense loving care and great dignity. They made a deep impression on Anne and as I learnt later from talking to some of the carers, she on them.
- *NHSCT Community Nursing Team (Waveney)* – Their daily visits to give Anne anti-coagulation injections for clots in her legs were heaven sent as we could ask them questions and get extremely helpful advice and reassurance. Additionally, they provided alternative solutions when Anne became too weak to go to the toilet. They recommended a top up mattress to prevent bed sores & glide-sheet to move Anne more easily about her bed. In Anne's last 10 days of life, they went *"above and beyond the call of duty"* telling us if were in any way concerned about Anne to ring them (on their own mobile phone) stressing there was no such thing as a false alarm! In her last week of life District nurses called with her several times a day.
- *Together the NI Hospice Specialist Nurse, NHSCT Homecare Team & NHSCT Community Nursing Team (Waveney)* –They enabled Anne to spend her last

weeks at home. This was truly immensely precious quality time for us as a family & close friends.

- *NHSCT Allied Health Professionals* – OT for provision of a riser-recliner chair, bath seat etc. Dietician – what food(s) to give.
- *Seven Towers general medical practice (Ballymena Health and Care Centre)* – All the staff were very diligent and supportive in Anne's final months of life regarding the many medication changes and referrals. Also, in the aftermath of Anne's death in looking after me.
- *NHSCT Hospital Diversion Team (at Rosedale, Antrim)* – Anne received a blood transfusion here. A "Domestic setting," transfusion given quickly and on time, no long wait in crowd hospital conditions.
- *Community pharmacy* – Recognised the urgency of dispensing scripts. Even delivered some to our home.
- *Dalriada Urgent Care (DUC)* – In an emergency out of hours DUC acted very speedily re home visit & arranging emergency ambulance to AHH ED

4) Anne's care and treatment – what went OK.

- Emergency Admissions – Early May 2023 for neuropathy (severe nerve pain). Early June 2023 for (ne)urosepsis. We are very thankful for the very prompt care and treatment Anne received in AAH ED.

5) **Anne's care and treatment – what could have gone better (especially communication issues)**

- *Reluctance of some hospital doctor(s) to engage with the family* on Anne's condition citing (mistakenly) patient confidentiality. I had enduring power of attorney (POA) to support Anne from April 2023.
- But even if I had not POA it is surely vital that families should be involved in the conversations about a person's care when they are so sick and frail. These discussions will help us understand what is going on, help us understand what support they can give to a loved one (potentially alleviating some of the pressures on the NHS) and help our family member decide on what is best for them out of all the options available. We recognise that there is not enough money in the NHS (and there never will be) to provide the level of care needed

by everyone. We recognise that as a society we all need to step up, but we need to understand what we can and need to do to help to help a loved family member who is terminally ill.

- We had great difficulty of contacting the part-time hepato-biliary special nurse at AHH.
- *Lengthy waits for infusions & transfusions at Laurel House*. No forward planning of treatments seemed to take place.

  E.G. June 8, 2023 – Laurel House (such that Anne was completely exhausted!). 5 hour waiting – home – bed- only to get a call from a junior doctor to get my wife to ED as her life depended on it! He would not listen to me as I explained Anne had just been treated. So, another trip to ED, a long wait only to be told what I already believed – a false alarm! But the impact on Anne was almost catastrophic. Next day she was an emergency admission to AHH with urosepsis.

  And 29 June 2023 Original 9 am *timing of outpatient appointment* at Laurel House was completely unacceptable (clashed with her carers & district nurse calls to our home). Rearranged for 12 noon and told would only take 1 hour. Anne was the last patient to be treated, leaving at after 3 pm.
- In early May 2023 we were informed that Anne would be *referred to NI Hospice*. We were *not told* that subsequently it did not need to happen at that point in time. So, for 3 - 4 weeks, as Anne's condition deteriorated, we were expecting contact from the NI Hospice, *but nothing happened*. I had then to visit my GP Practice ask them to make a referral - which they speedily did. We could have done with the hospice specialist nurse inputs weeks earlier.

6) Our Suggestions for Improving Palliative Care in NI (based on our experiences)

- *Consultants need protected time to plan ahead for the care & treatment of patients.* Our NI hospice special nurse knew Anne's blood tests results before she would attend outpatients at Laurel House. But workload pressures seemed to mean that consultants were only looking at these when Anne was in front of

them. Then the necessary blood transfusions etc had to be ordered. This took time & in our view significantly impacted Anne's health.

- *Greater use and development of Hospital Diversion teams model* (example of Rosedale or hospital at home) would be a really positive step and help alleviate pressures in the acute hospital.
- *Improved communication between hospital staff and terminally ill patient families* – whilst we have seen the immense pressures staff are under this is in our view absolutely critical e.g. Information about what pain relief had been given and when; what referrals were being made and to whom (especially if changes are made to what was originally agreed) etc. It is our experience *Communication pathways between clinicians need to improve* so everyone has access to all a patients records and are also aware of the patient's wishes.
- The *minimum treatment* for any patient admitted to hospital is to *control their pain*. Anne was admitted to hospital (June 2023) she was told that she had had the maximum amount of pain relief. We understand the pressures NHS staff where under that weekend, but it is our opinion that any patient admitted to hospital and who is in severe pain should have a *written pain plan* put in place with clear instructions for staff on what to do if things are not working.
- *The NHS needs to provide Contextualised Care*. We had doctors talking about doing repeated tests and treatments that were never going to improve Anne's quality of life and had an extremely negative impact on her at the end which in our view did her no favours.
- *Capacity of MacMillan Palliative Care Unit at AAH needs to be increased* – Before 12/7/23 the waiting list for admission was three patients. Over the next few days this trebled in size. Anne was offered a place the day before she died (17 July) but was far too weak to be moved even by ambulance.
- *Increased funding of Hospices etc*. – We understand that at present only about 25% of funding comes from the public purse so these organisations are very much dependent on public donations for the overwhelming majority of monies. Indeed, we understand that the lack of funds means that some palliative care beds are moth-balled.
- We understand from NHSCT that *business cases for a Cancer Clinical Nurse Specialist workforce plan* for each of the Trusts was submitted to DOH originally

in 2022. A small number of vulnerable temporary funded posts are currently being addressed **but** the wider workforce expansion in cancer CNS still needs addressed by the Department of Health. These posts we were told are *keyworker posts* whose role includes supporting cancer patients and their families, supporting the clinical team at clinic and ward level, prescribing competencies, follow up review and an education role for the multi-disciplinary team for the benefit of patients and families.

7) Closing Comments

Big Picture (strategic) - Each year around 4,500 people in Northern Ireland die from cancer. About 25% of the total number of deaths. In addition, there are other people with life limiting conditions who need palliative care as well.

Small picture (our experience) - If you tick all the boxes for a particular illness e.g. breast cancer, the patient journey is very smooth. However, if you do not tick particular boxes then that journey is much more challenging and we felt that there no one wanted to take responsibility for Anne's case. Yes, we know that the outcome would never have changed in her case, but *the journey could have been much more straightforward*.

I hope you will agree that our society is judged by how it treats its most vulnerable. When I worked in the local Health & Social Services the strap line or motto about why we existed was, **"Adding years to life and life to years."** We as a family are so thankful for all the help and support we received. We do not know how we would have coped without it. It gave us precious quality time to spend with Anne as her health rapidly deteriorated. Sometimes weeks, even days, are as important as years!

Thank you so much for listening to my testimony about a truly extraordinary, beautiful lady, my wife Anne. We loved her and miss her loads.