



BSH Heart Failure Nurse and Healthcare Professional Study Day 2017

Presentation title: The Final Wish

**Speaker: Pearl Lesson – Heart Failure and Arrhythmia Nurse Specialist
Poole Hospital NHS Foundation Trust**

Conflicts of interest: None declared



Patient History

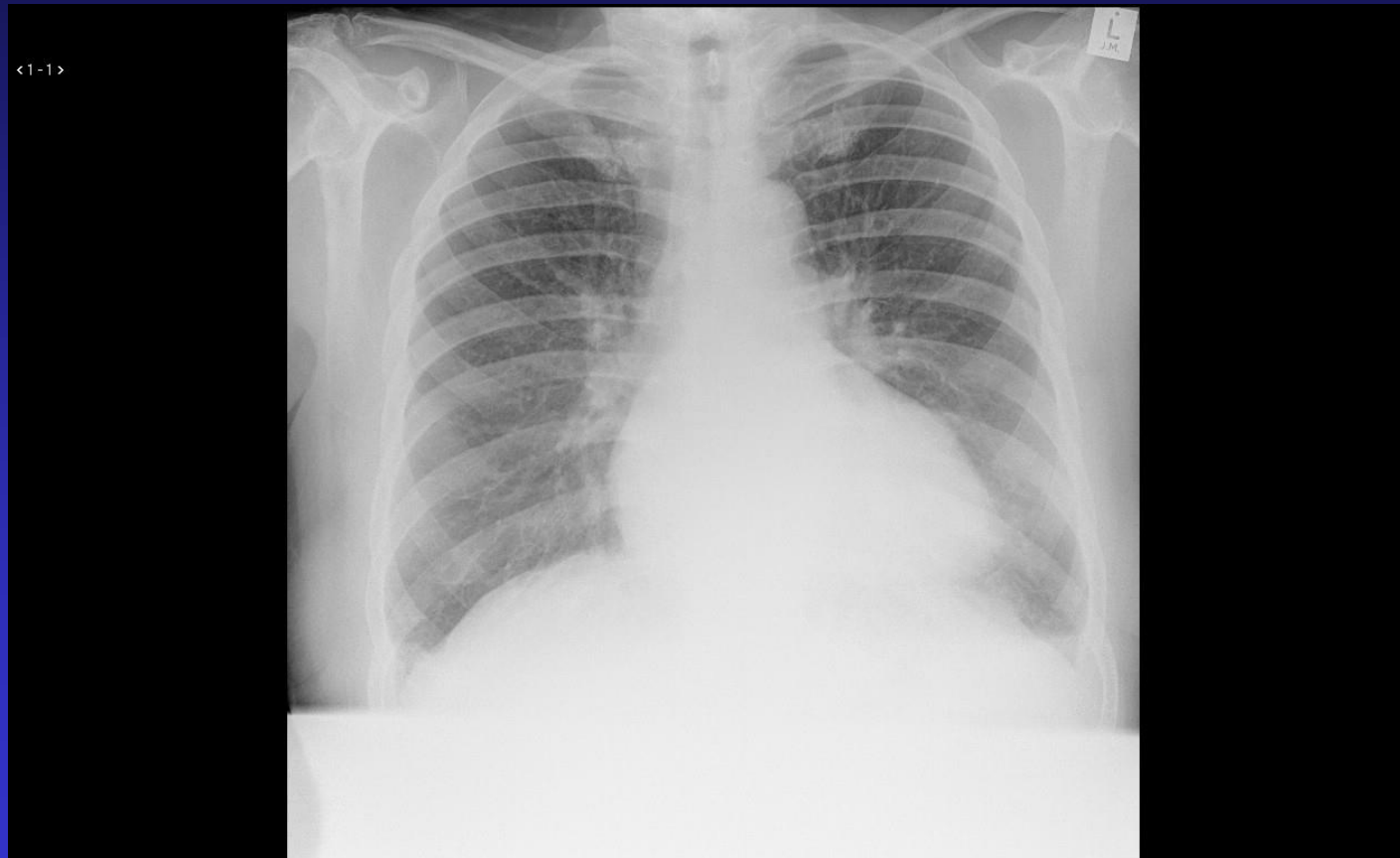
- Susan (58)
- PC: 6/52 hx of ankle oedema and dyspnoea on exertion
- PMHx: Essential thrombocythemia, AF
- Mx: Hydroxyurea, Warfarin, Digoxin
- SHx: lives with husband, non-smoker, works fulltime, social drinker
- FHx: Mother (81) angina and PPM, Brother AF



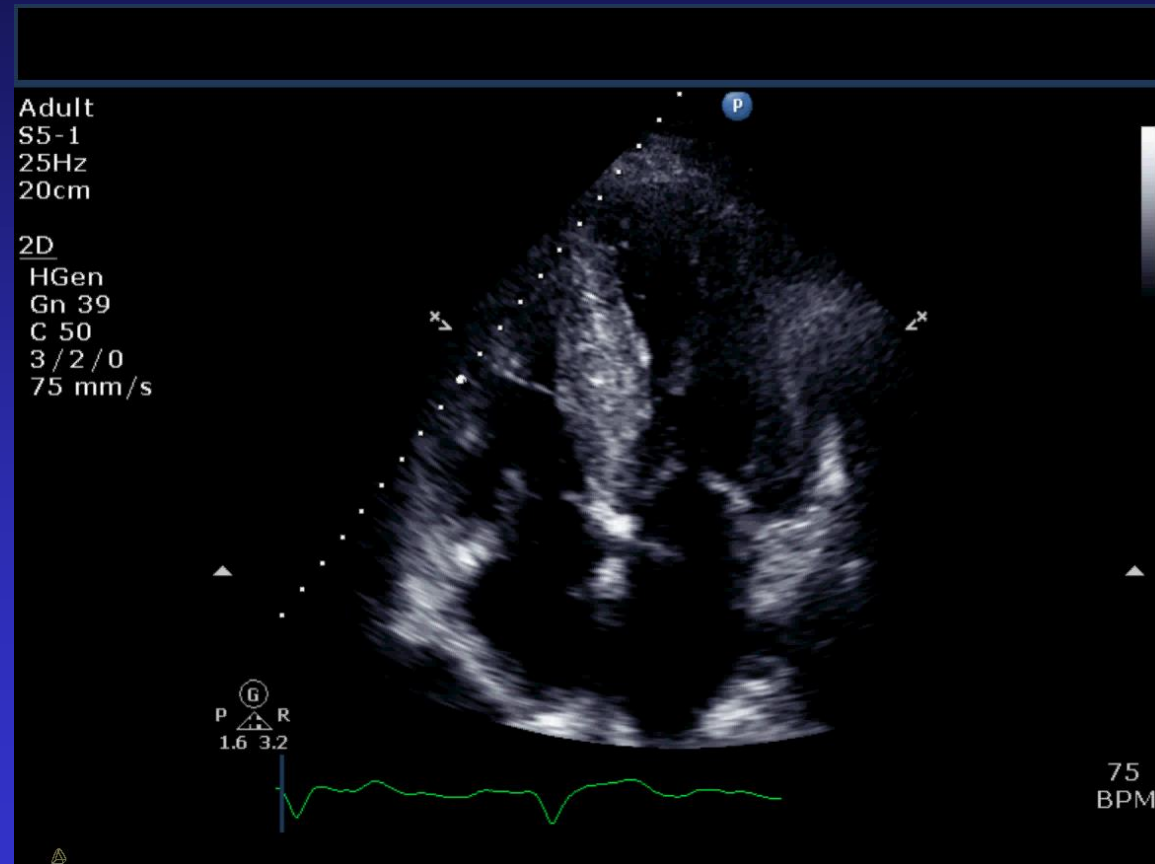
Physical Assessment

- Not short of breath RR14, O2 sats 98%RA
- Bp 102/63 P 84irreg JVP ↑7cm HS I+II
- Chest – loud breath sounds with reduced a/e bi-basal
- Abdo – soft, not swollen
- Calves non tender, Leg oedema to both knees
- Weight 65.1Kg

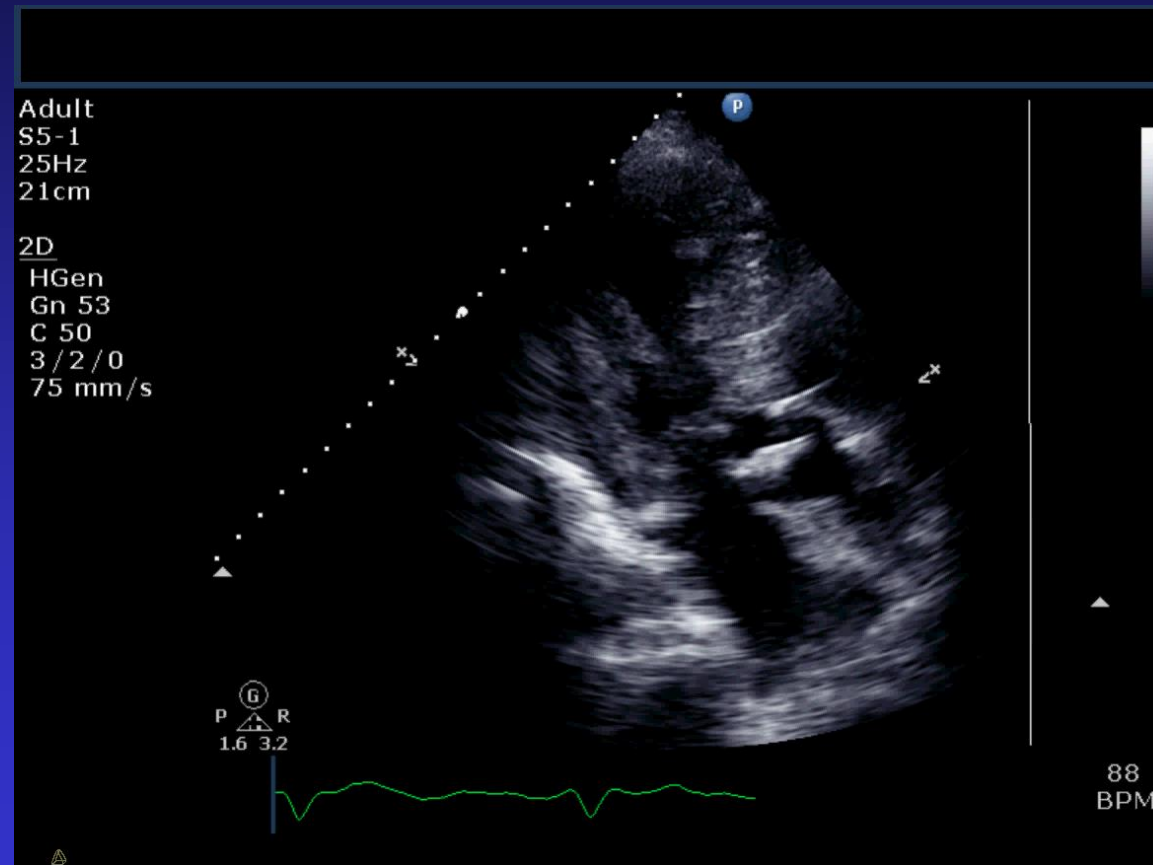
Chest X Ray



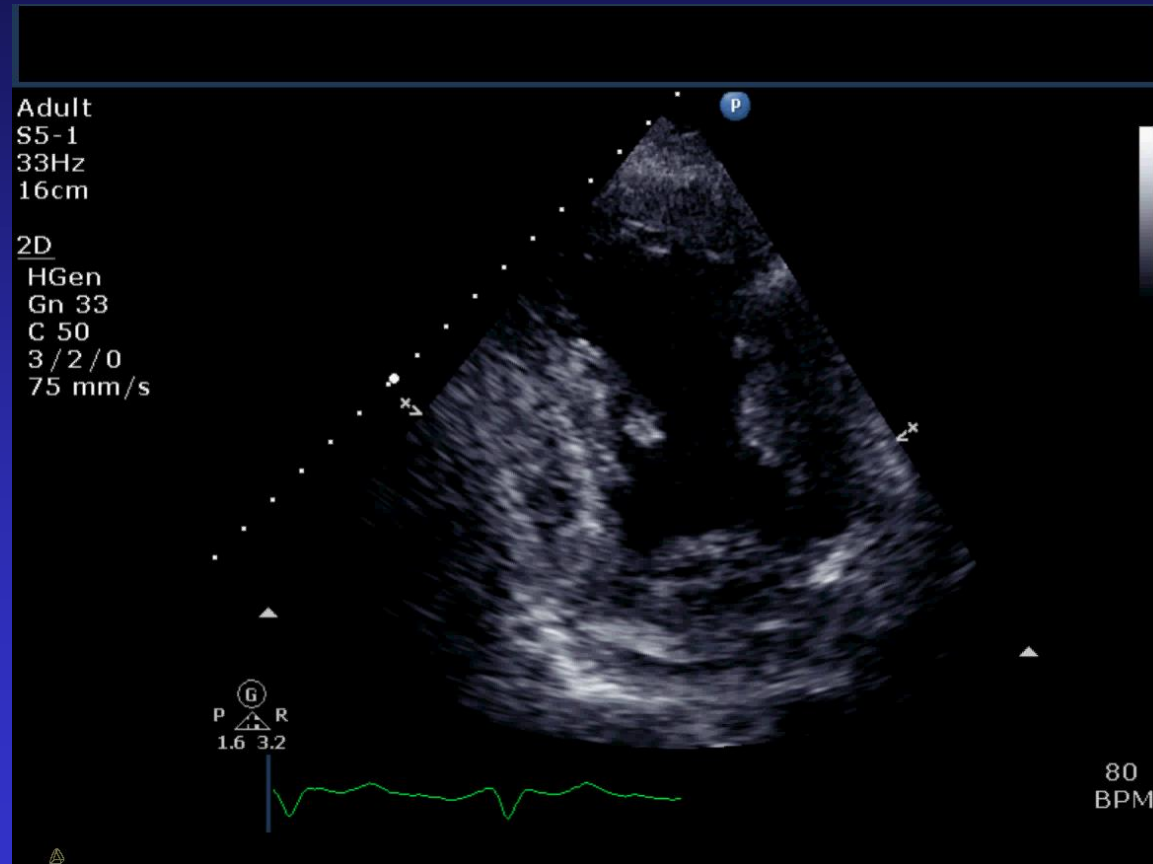
Apical 4 Chamber View



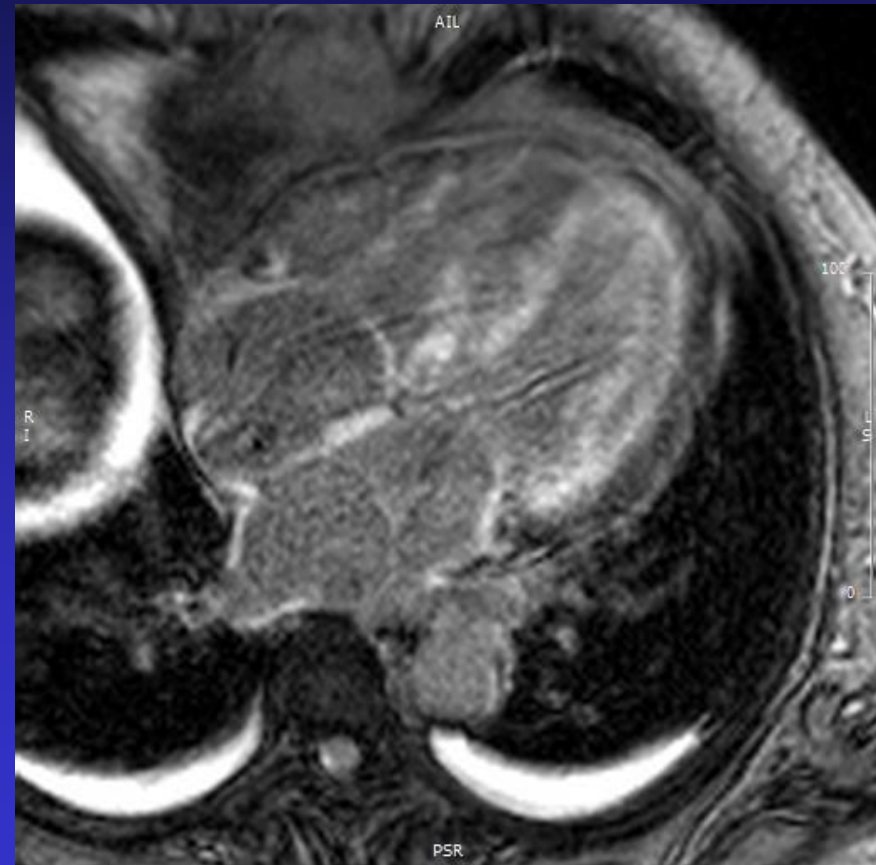
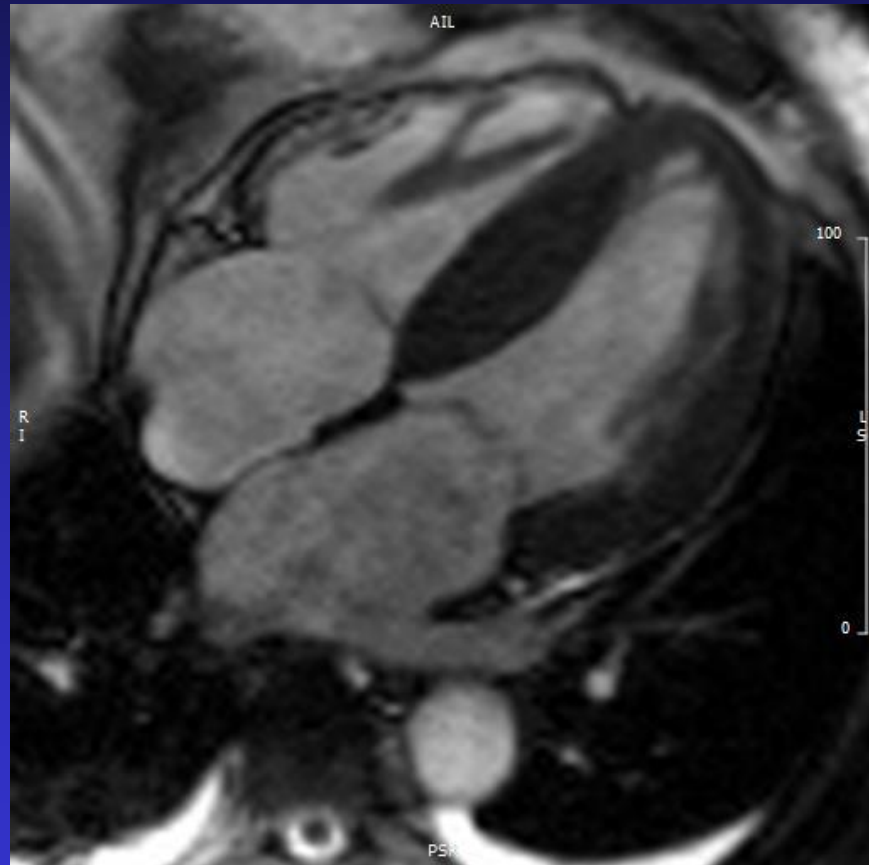
Apical 3 Chamber View



Apical 2 Chamber View



CMR imaging





Other investigations

- ECG: Atrial fibrillation, rate 90, LAD, LVH, low voltage in the limb leads
- Bloods: Hb normal, MCV 112, INR 3.2, ALP 127, Alb 34, U&E's normal
- CTPA: no PE, small bilateral effusion
- Raised Lambda light chains -350



Next step

- Discharged home with Furosemide, Spironolactone, Bendro., Digoxin, Warfarin, Hydroxyurea
- Referred to Haematologist
- Informed findings of the investigations are consistent with Amyloid
- Referred to the National Amyloidosis Centre



National Amyloid Centre Assessment

- Macroglossia
- Weight 60.8Kg, moderate oedema, Pulse 80irreg, BP 100/70
- JVP markedly elevated, HS I and II, Chest clear, Abdo soft with palpable liver edge
- NTproBNP 2515 pMOL/L
- SAP scan – no visceral amyloid deposits, congested liver



National Amyloid Centre Assessment

- Diagnosed with Cardiac AL Amyloidosis
- Advised extremely poor prognosis if left untreated
- Advised Haematologist's to start Velcade and Dexamethasone
- Referred to Community Heart Failure Team



Initial HFNS visit

- Bright, bubbly and full of humour
- Bilateral leg oedema to the thighs
- “little bloated”
- Breathless getting in and out of the car
- 2 hours to wash and dress in the morning due to fatigue and dyspnoea
- Nocturnal cough with one pillow
- Weight 60.8Kg (BMI 22.3), BP 92/60, P 66-75 irreg



The Early Weeks

- Started Chemotherapy 10/07– felt extremely tired
- Good and bad days with breathlessness
- Weight stable – 59.4Kg
- Thirsty - ↑fluid intake – diuretics adjusted
- 1 week later – Lethargic, nauseated, “floaty”, ETT 20 yards –BP 70/50
Weight 57.6Kg
- 11/07: Tearful and upset - giving up work – “on the downhill”
- Muddled – feeling low and upset –Toby died – Na+127- GP stopped Dig
- Chemo changed to Thalidomide, Cyclophosphamide and Dex
- 12/07: In bed for 3 days – frail, rings falling off – DN to do bloods as
unable to see GP



The Talk!!!

- 01/12: admitted over Xmas with postural hypotension –
Thiazide stopped and Loop↓
- More bad days than good
- “Quality rather than quantity”
- Cagey about weight
- Husband very tearful, finding it difficult coming to terms with prognosis – feels he should be with her all the time
- Something to look forward too



The Coming Months

- S/B Haematologist – Chemo altered
- Family holiday to the Lake District 03/08
- Admitted with weight gain, abdo distension, dyspnoea, low appetite
- LV EF<20%, LBBB on ECG
- Referred for Transplant assessment
- Out and about with friends and family
- Holiday to France 09/08
- NAC 10/08: Partial remission NTproBNP 912



The Coming Years

- 08/09: GI bleed and acute renal failure
- 09/10: # Rt olecranon – open reduction
- 6 monthly visits to NAC - NTproBNP 468-912
- SBP 97-105, Weight 54-64Kg
- Furosemide 80, Dig, Bendro prn, Spiro 50
- Alopecia
- More holidays to France
- Son's wedding, Birth of Grand-daughter, The IVY
- Enjoying life – lots of food and lots of shopping



2012 – Annus Horribilis

- March – INR 10 – nose bleed
- March – Loose diarrhoea post chemo
- March – Worsening peripheral oedema
- April – Mild cellulitis
- June – Lethargy, malaise, diarrhoea following sore throat
- October – Fall – scalp laceration
- December – Fall – scalp laceration

Further conversations re prognosis and end of life by HFNS & GP

Referred to Palliative Care



2013

- June : NAC NTproBNP 2626
- July: # Lt distal radius – conservative tx
- 22/08/13: Worsening shortness of breath, JVP ↑5cm, P 110, BP 80/50, Ascites, Large effusions



Off to CCU

- 28/08/13: Set to go home - spiked temp, BP dropped – Dopamine
- 01/09/2017: Wanting to go home – told unable to go due to Inotropes and Furosemide
- 02/09/13: “I want to die at home”
- 03/09/13: Lots of discussion with family, Cardiologists, GP and District Nurses re practicalities
- 04/09/13: Cardiology sPR – “advised against going home as if she were to go home, inotropes will be switched off and she will die quickly. Asked family if they felt it appropriate to transfer unwell patient across the county for a few minutes at home. Informed family and Susan she was unlikely to survive journey”



The Final Journey

- 4th Sept 2013 1300: Susan discharged on Dopamine 10mcg/kg/min and Furosemide 240mg in 24hrs



Final hours

- Susan spent the afternoon among her family and friends sitting in her favourite chair with a fine glass of red
- GP arrived at the end of surgery
- The Furosemide and Inotropes were stopped
- The next morning she was sitting up in bed – “I’m fine”
- Susan spent the day resting and catching up on all the gossip
- 4th September 2013 – Passed away peacefully in her sleep



Final thought

How many people were involved in Susan's Journey?