



From HD to PD

A patient's journey from a
mother's perspective

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Objectives



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- To follow a patient's medical journey from the beginning to present time.
- To understand a mother's perspective of her child's journey.
- To view the support available to renal families at the trust.
- To learn from a mother's experience for service improvement.

Background



- 4 year old girl
- Single parent household – 5 siblings
- Previously on Child In Need register – Social Services Support
- Bilateral FSGS/Mesangial Schlerosis
- Wilms Tumour Rt Kidney
- Anephric
- Renal restricted diet, nutritional supplement-total fluid allowance =300mls
- Small for age-growth hormone not yet-chemo
- Currently on PD
- Preparing for transplant

Medical journey

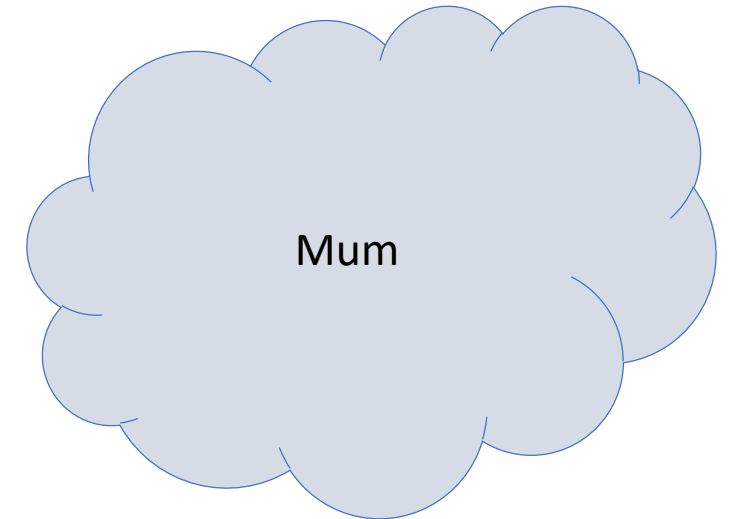


- Weight loss → H/V → Wt Clinic
- Delayed mobility @1 yr
- Weekly GP visits – Chest infection
- Local hospital → viral → home
- GP → Tertiary Hospital PICU → MRI → Kidney tumour
- Transfer Specialist Hospital → Chemotherapy →
- Bilateral nephrectomy → HD → CVAD X2 → AVF
- AVF Failure → PD

Wilms Tumour and Nephrectomies



- Terrified
- Freaked out – “ C “ Word
- Guilt
- Relieved – Take the “C” away
- Questioning- How to survive without kidneys
- No prior knowledge of dialysis
- Modality option not given
- No knowledge of HD impact



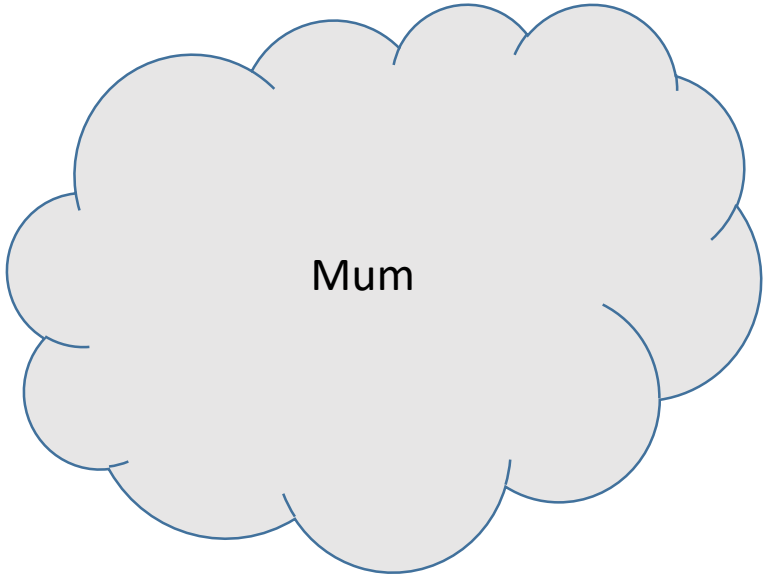
HD experience

- Initial HD in one unit –Chemotherapy in another
- Isolation at first
- 3 X Weekly - Reality
- 4 -5hours per session
- 4hrs journey to unit each day - tiring
- Carer for 2 visits/week
- Separation from siblings - panic - unsettling
- Challenges with fluid removal – physical changes on the machine
- CVAD (X2) accident, thrombi
- warfarin
- AVF bleeding, thrombi



AVF experience and Thrombosis

- Safer than CVAD
- Better dialysis
- No more worry about line
- Blood loss due to warfarin
- Felt safe it happens in hospital
- Devastated at the loss of AVF
- Happy when PD was mentioned
- “at least we have been given another chance and choice”



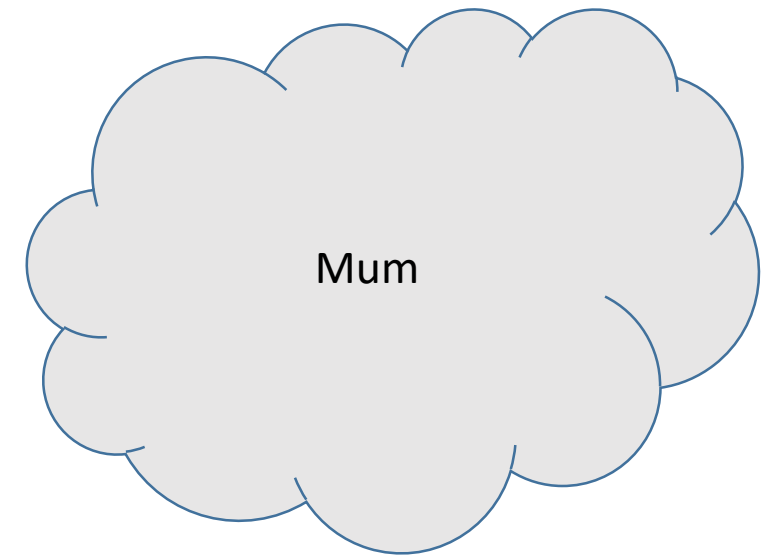
PD experience

- Training at the hospital
- Dialyse at home
- 7 nights
- Assisted PD
- Carer 18 hours
- Weekly clinic
- Weekly bloods
- PD deliveries at home
- Local pharmacy – meds & Supplements



The question of PD

- No PD if Fistula worked
- PD not offered due to level of illness
- “If I knew then what I know now”
- Anxiety
- “if I mess it up at home it will be my fault”
- “Don’t like dressing change”
- Assisted PD = “God sent”
- Support from Nurses, Carer, APD and Family



Difference between HD and PD



- Quality of life - social
- Empowerment-control, understanding, initiative, assessment, feedback.
- Interaction with siblings – blossomed – personality – language development
- Education – enjoying school – interaction -learning
- Clinic visits- fewer, PD monitored
- Acceptance of new way of life

Support available

- MDT – Dr's, nurses, pharmacy, dietician
- Financial – Transportation
- Psychology
- Play therapy
- Communication- Leaflets, meetings – reiterating info
- Community team
- Other families



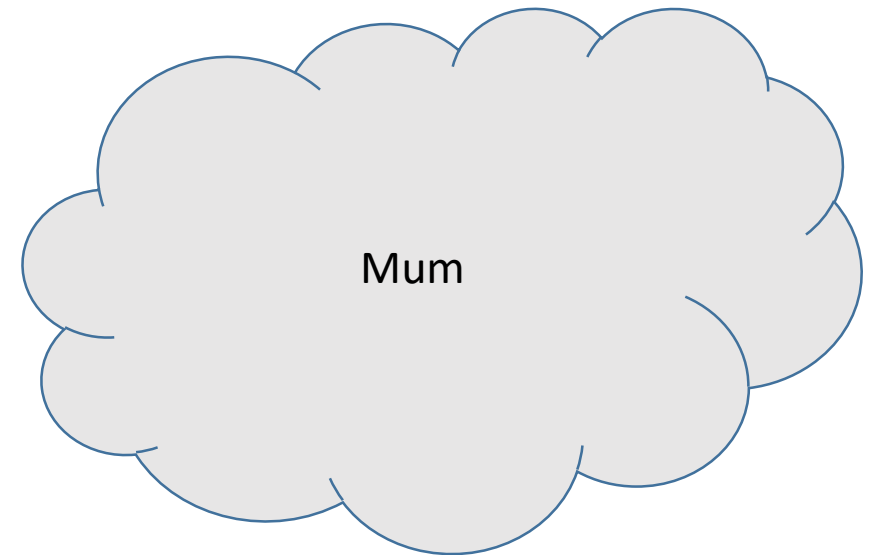


Current situation

- Preparation for transplant
- Immunisations – almost completed
- Donor – live/listed
- Personal plan to be devised, refined and agreed with parent , carer and staff

Moving forward

- Tx- Don't expect a match straight away
- Waiting list- waiting game cont.....
- Post Tx – “Nightmare at first”
- Storm before calm
- Future – benefits from her experience
- Mum- “old and wrinkly”
- Advice other parents to ride the storm and stay strong
- “Thank team for putting up with me”



Any Questions

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