What I tell my patients

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Overview

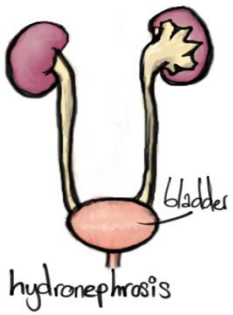
- Local practice – I see all patients for follow up but antenatal counselling shared; 100 new patients per year
- General approaches
- Specific approaches
- Parent feedback
- Top tips

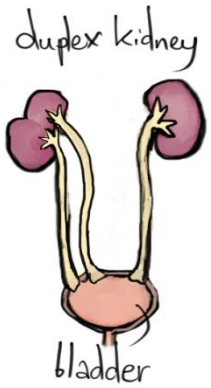
My concern

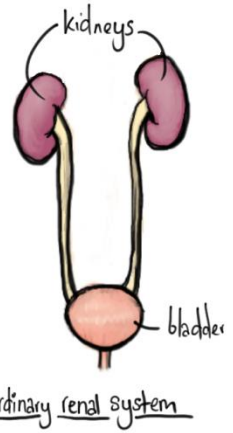
General approaches

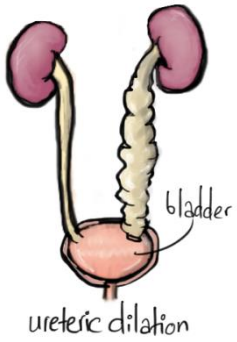
- Usually given advance notice of problem
- Chance to review guideline and or obtain additional information
- Take generic information sheet plus additional pictures
- Generic counselling models eg SPIKES depending on nature of condition
- Sometimes wipe on/wipe off tablet
- Complete antenatal referral form and or letter

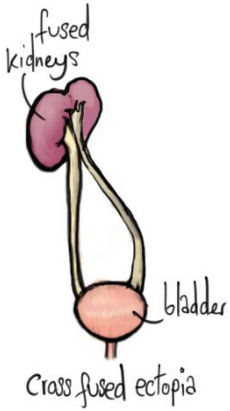
A picture paints ….

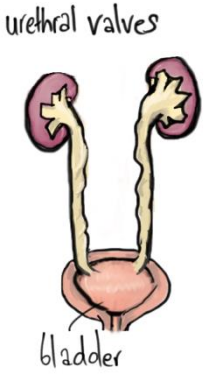




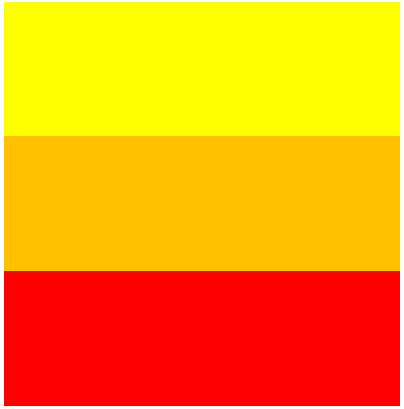








Types of referrals



High chance of normal outcome
Includes – ectopic kidney, renal pelvis dilatation

Increased morbidity – bilateral cystic disease, prune belly syndrome

Increased mortality – renal agenesis, severe tract obstruction with poor liquor volume

‘Serious’ cases

- Journey from shock grief and naivety about diagnosis to decisions about continuation or not of pregnancy.
- Lot of self blame and guilt, isolation and fear for future.
- Parents say doctors talk too much during initial consultation, over use scientific language, can be vague or overly confident, don’t provide ability for rapid access.
- Listen for clues as to how much information is required.
- Overview generic questions from parents from ‘baby’ point of view – visiting, feeding, involvement in cares

‘Serious’ cases

- Confer and offer realistic survival statistics
- Consider place and mode of delivery
- Consider perinatal palliative care, advanced care plan
- ‘trial of life’ try and be clear what is involved and that care plan is available and other members of team fully informed
- Consider direct referral to palliative care and or visit hospice

Moderate cases

- Consider mode and timing of delivery (increased risk of respiratory support with premature delivery, increased when not in labour)
- Consider antenatal steroids if early delivery is planned
- Antenatal care planning with urology/ nephrology
- Explain that things might not get sorted straight away
- Discuss breast feeding support
- Consider visiting neonatal unit and speak to support team

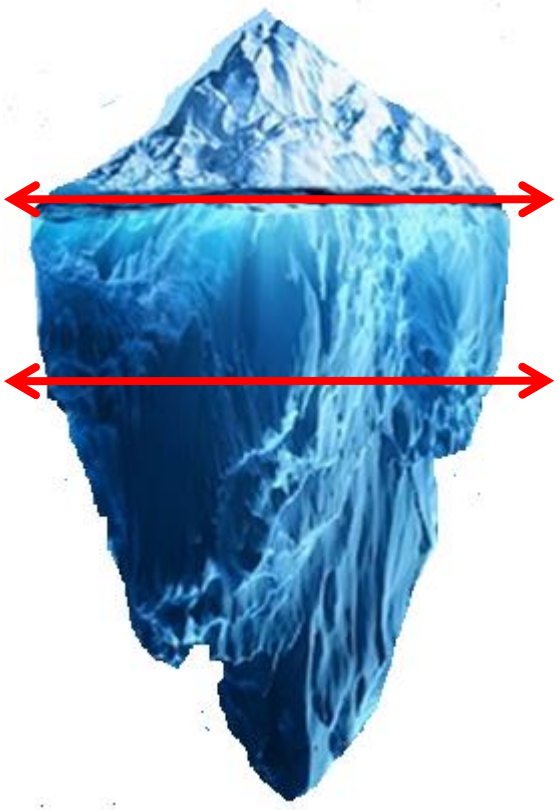
Low risk cases

- Explain possible diagnoses and outcomes
- Offer reassurance and explain postnatal referral pathway
- Use parent information sheet
- Keep updated

Low risk cases

Antenatal Diagnosis	Parent comments
Unilateral renal agenesis	'I was heart broken' 'The first thing we did when we got home was to contact our family to see if anyone would be a kidney donor'
Unilateral renal pelvis dilatation	'They don't say much except not to worry. Then you get home and check the internet and you are worried' 'They just didn't tell us anything really … just that it probably wasn't much to worry about'
Pelvic kidney	'they didn't really say very much. I searched it myself and found the answer.'
Single renal cyst	'we asked to speak to someone but we were told it wasn't necessary. When we went on the internet we freaked out'

Lessons from NTD/ CDH



Don’t underestimate parental anxiety

Archie – renal pelvis dilatation 7mm 20 weeks 9 mm 2 last trimester scans, normal NIPE, normal stream

Postnatal follow up – serial scans increased to 12 mm, 10 and then 8 mm, good symmetrical interval growth, discharged

Mum - broke down in tears; thought about termination, relationship difficulties partner thought she was unnecessarily concerned, counselling. Relieved but angry.

Conclusion

- Spectrum of concern – try and make sure your spectrum matches the parents
- Consider using generic counselling approach
- Offer use of handouts if appropriate
- Don’t forget the importance of specialists for difficult cases – ideally in a joint consultation
- Don’t forget the importance of neonatal issues and newborn parent issues