

# The Role of a Nurse Specialist in a Li Fraumeni Service: How we can make a difference

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# Who Are We?

- Consultant Oncologist
- Nurse Specialist
- Clinical Geneticist bi monthly
- Slightly different to other services, run by a paediatric oncologist rather than geneticist.
- Psychologist needed!



# Why is a Nurse Specialist so important?

Well recognised that the CNS is invaluable in any cancer service

- 2015 – Clic Sargent Keyworker Project implemented keyworker posts in children's cancer services
- 69.7% of patients questioned who had a Key Worker had an improved peace of mind
- 55.8% feeling less stressed
- 86.9% reporting the model improved coordination of care



# TP53 Surveillance Clinic

- Toronto Protocol
- Full body and Head MRI yearly
- 4 monthly abdominal Ultrasound scan
- Flexibility around scans
- Referrals taken from all over the country
- Big co-hort from London, Greater London, North East and Yorkshire at present
- Children 0-18 years of age
- Discharged to adult services at 18.



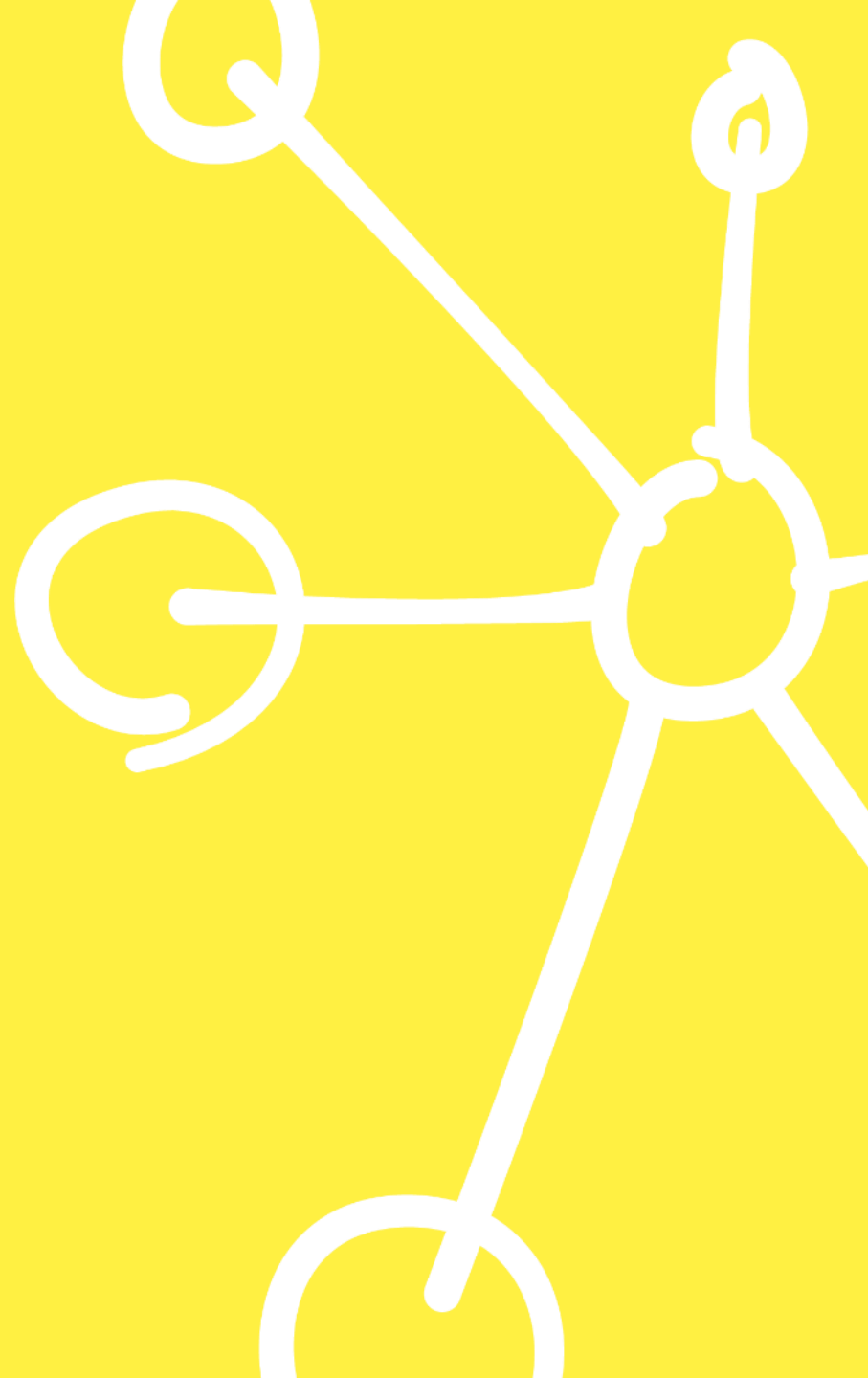
# TP53 Surveillance Clinic

- Children must have a TP53 mutation confirmed prior to commencing the surveillance
- We can offer predictive TP53 genetic testing at GOSH or this can happen locally
- 1 clinic a month at present (moving to 2)
- 70 children currently in clinic for surveillance



# Role of Nurse Specialist

- Key workers
- Communication / building relationships
- Support and advocate for child and family from first visit in clinic to discharge
- Leaflets /information prior to first visit
- Information providers throughout journey - signposting
- 9-5 Monday to Friday access to Nurse Specialist
- Direct point of contact for the families
- Telephone support whilst outpatient and face to face support when in hospital





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# Role of the Nurse Specialist

- Education focused clinic – red flag symptoms
- Physical examination offered every clinic, either by myself or Consultant
- Ensuring a positive clinic experience – families with us for potentially 18 years!
- Parents can contact myself if concerned between appointments if any concerns

# Role of the Nurse Specialist



- Direct point of contact to somebody knowledgeable who can help.....
- Recent examples include -
- Breast Lumps
- Seizures
- Leg pain
- Eating difficulties
- Headaches
- Lumps and bumps





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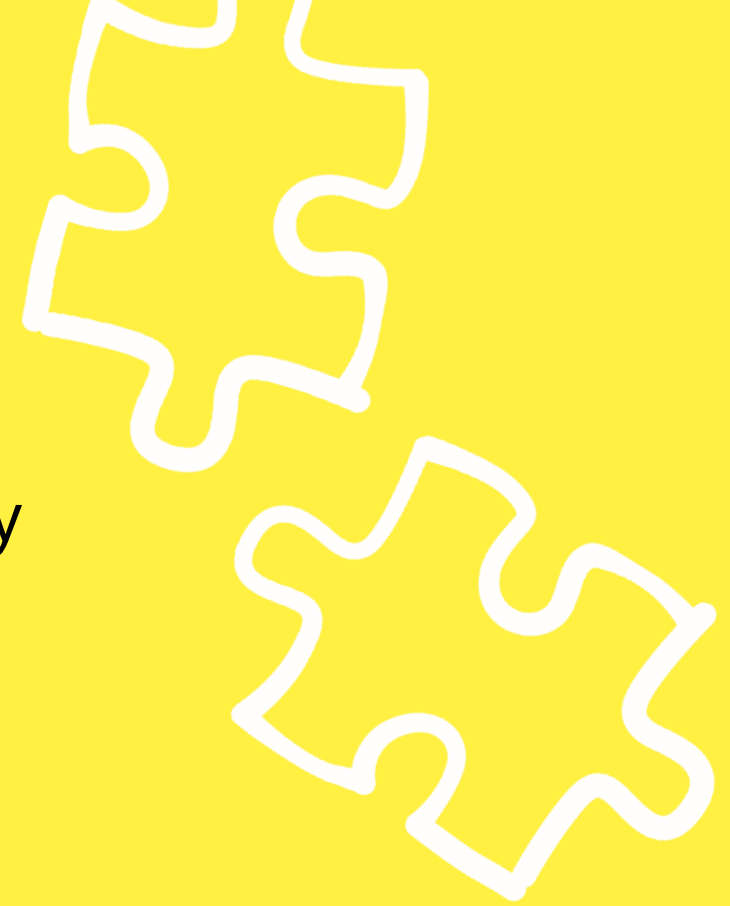
## • **Role of the Nurse Specialist**

- Health professionals frequently contacted by myself on behalf of families to request appointments – made worse by pandemic
- Psychological support – parents phone away from clinic setting for advice around talking to their children / troubles at school / mental health/ family issues
- Psychologist within this clinic next step forward in service

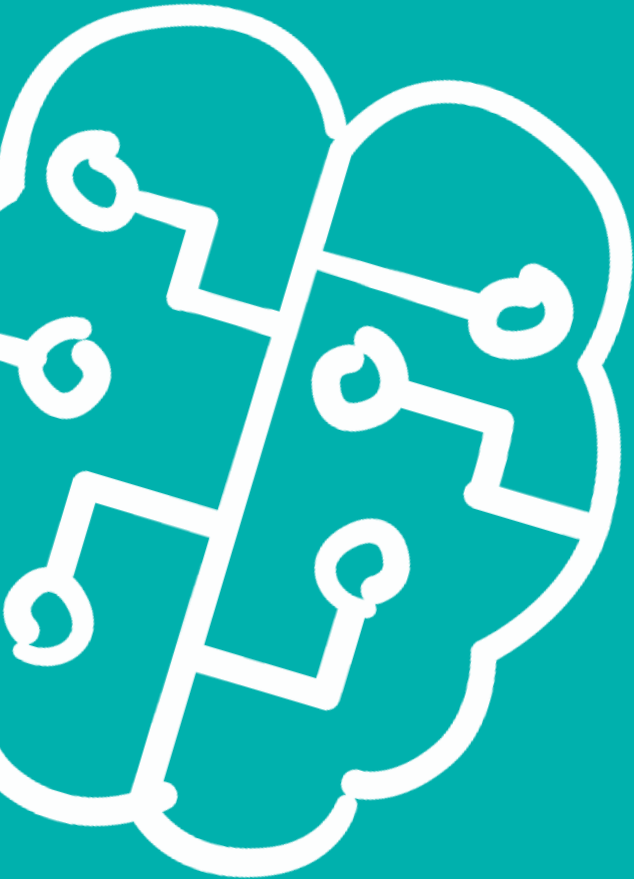


# Role of the Nurse Specialist

- Care co ordination with local services – takes away stress for families
- Co-ordination around scans
- Now offering accommodation for families outside London for scan appointments
- Discussions / support GA v sedation v awake scans
- When is the right time to start MRI scans. No right or wrong, supporting families to make the right decisions for their child
- Individualised care



# Extended Skills



- Masters Pathway
- Nurse Prescribing
- Physical assessments
- Supporting Research
- Families seen and assessed consistently by a CNS who they know and trust

# Challenges in older children and teenagers

- Anxiety around scans and what they might pick up
- Feeling different than peers – potential issues at school and behaviours at home
- Often have knowledge of cancer / what it is / that they are at risk.
- Worries about their future and having their own children
- Feelings and emotions around TP53 mutation



# Challenges in older children and teenagers

- May have already been through a cancer diagnosis
- May have already lost a sibling / mother / father / family member / somebody important to them
- Emotions of why they are in this clinic but perhaps not their siblings
- Challenges around multiple siblings in same clinic appointment – differing ages often means different needs / conversations



# Challenges in older children and teenagers

- Cannot forget the children at home who do not have a mutation. How they feel that their sibling may develop cancer



**Any Questions?**

