

What do they do all day?: The role of the Metabolic Nurse

Jacqui Robinson

Genetics and Metabolic Nurse Practitioner Sydney
Children's Hospital

Metabolic and Mitochondrial Disorders

Numbers of children and adults diagnosed is increasing

This is due to

- Better diagnostic methods

- Greater awareness of disorders by others

Clinics are getting busier

- More patients

- More therapies

Need more staff to manage the patients

Number of Metabolic Nurses is increasing around Australia

Still not exactly clear what we do

Each service is slightly different and has slightly different needs

I will give a general overview and talk about my specific role

Metabolic Nurses

All senior nurses with at least 5 years postgraduate experience

Most Metabolic Nurses in Australia work in Paediatric Hospitals

Most are full time or close to

All work as the link between the Metabolic Team and other specialties

Act as clinic coordinators and complex case managers

Work closely with General Paediatricians and GPs to manage care

Clinic Appointments

Triage clinic appointments

Nurses will either book the clinic appointments or triage the appointments

If you need to see the team sooner than your scheduled appointment speak to the nurse

Help coordinate appointments with other specialties

Help to organise links with Allied Health Professionals

Help to obtain correspondence and results from other services

On Clinic Day

Most of the work will have been done before and after clinic

Can help with IPTAAS forms and attendance certificate

Often see families with Allied Health Professionals

Often used as Child Life Therapists

After Clinic Day

Often the family's interpreter

- Help to clarify anything that the family was not sure about

- Help to reinforce any management

- Help to organise other appointments if needed

Make sure that all correspondence is sent to the appropriate individuals

Liaise between members of the health care team to ensure that everyone is informed

Non appointment time

Organise scripts

Organise blood test forms

Organise results to be sent

Organise education for schools/pre-schools/community groups

Discuss research trials and options

Nurse Practitioners

Write Scripts

Write blood test forms

Give medical advice

Refer to Allied Health

Genetic Counsellors

Provide genetic counselling for parents, siblings and other family members

Organise cascade testing for other family members

Explain genetic results

Australian Genomics Health Alliance

National research collaboration between clinicians, researchers and diagnostic geneticists

Number of different rare diseases flagships

One for mitochondrial diseases

Specific criteria to be involved in AGHA

NSW Clinical Lead

A/Prof Carolyn Ellaway

NSW Genetic Counsellor

Kirsten Boggs Kirsten.boggs@health.nsw.gov.au

Questions

?????????