

The education of paediatric endocrine nurses and advanced level practice in the UK

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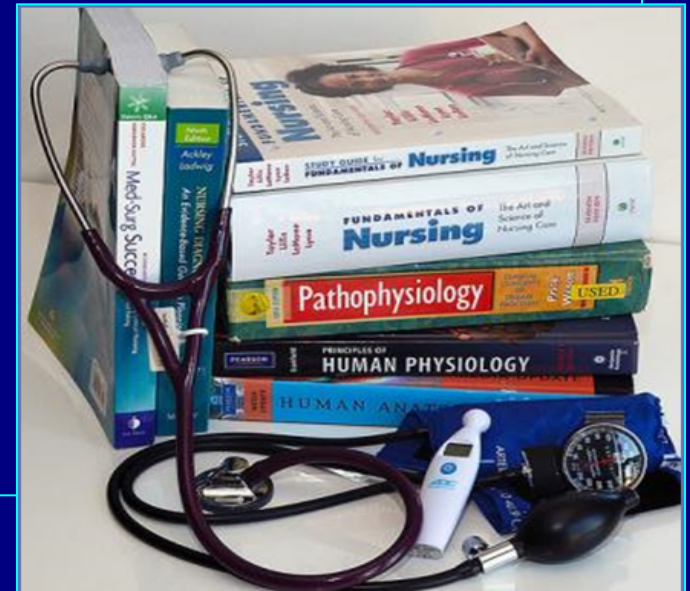


Introduction

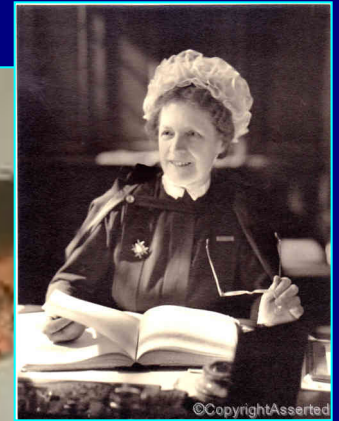
- History of Nursing
- Nursing Today
 - Autonomy and Advanced Practice
- Clinical Nurse Specialist Roles
- MSc Advanced Nurse Practitioner
- Paediatric Endocrine Nurses education
 - MSc Children's Nursing
 - Clinical Nurse Specialist
- Roles for Paediatric Endocrine Nurses
- Nurse Led Clinics

History of nursing in the UK

- 1990s
 - Diploma 3 year training
 - Post graduate education introduced
- 2000s
 - All graduate profession
 - Training university based
 - MSc level education
 - Doctorate/PhD



Nursing stereotypes



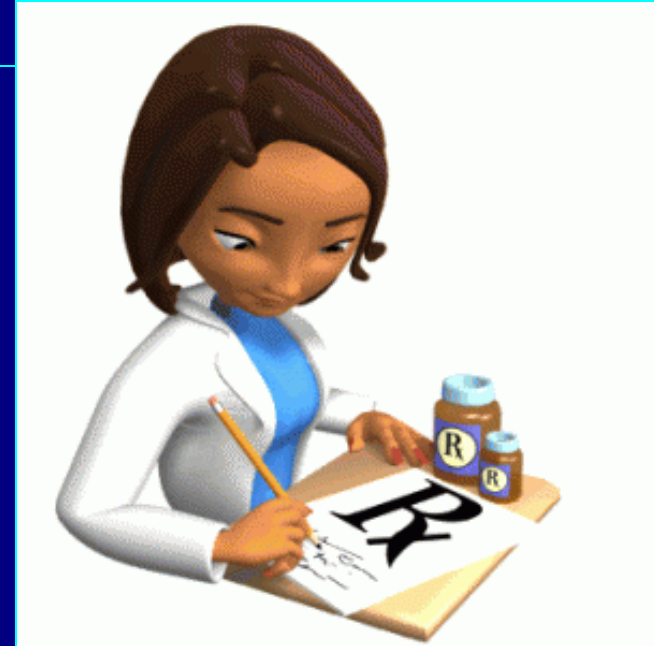
Nursing stereotypes

- Doctor's Handmaidens
 - Do nurses actually work *for* doctors
 - Training and education
 - Recruitment
 - Management structure
 - Co-workers
 - Daily care of patients
 - Liaison between patients and doctors
 - Autonomous profession

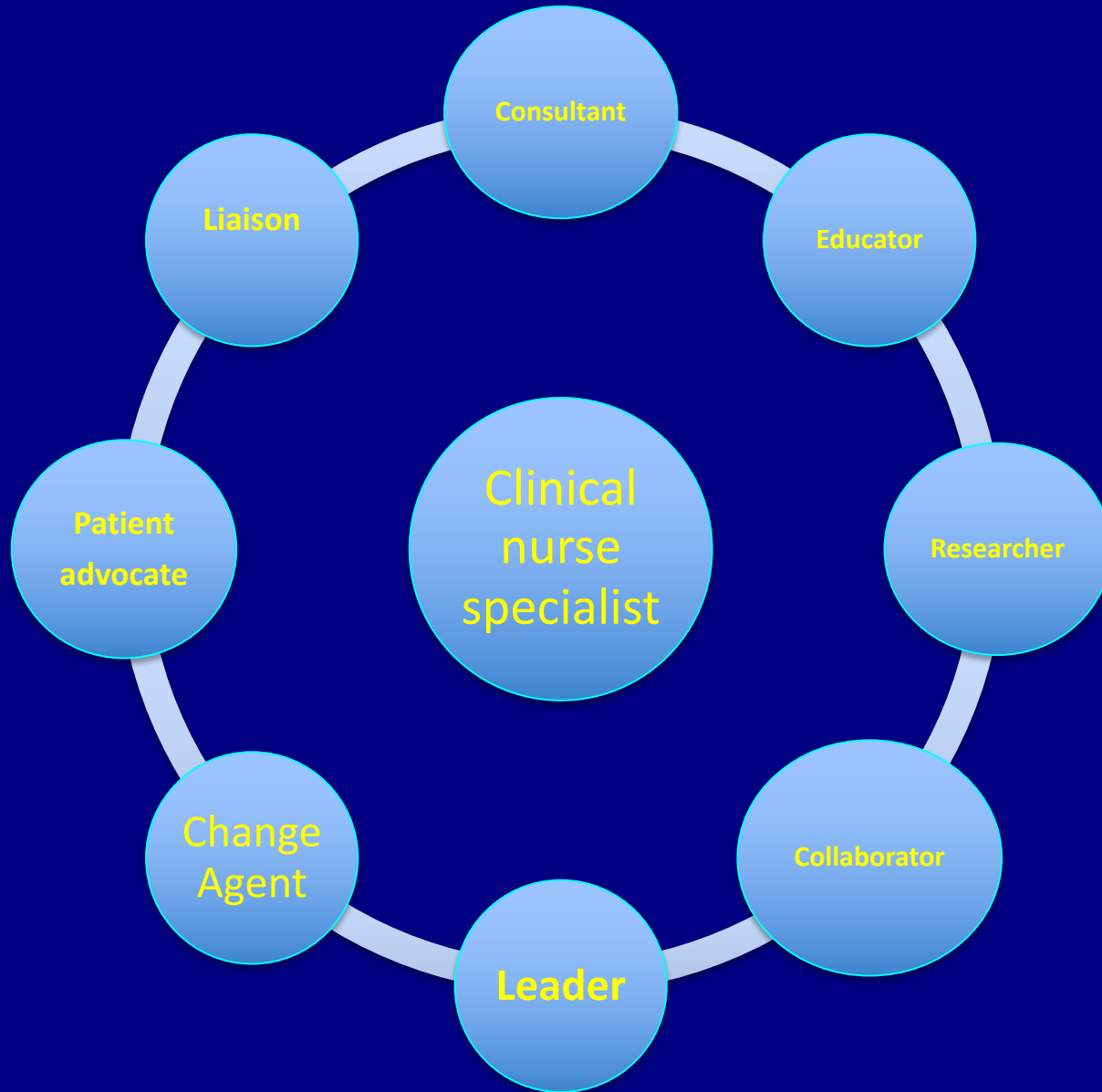


Autonomy → Advanced practice

- Clinical nurse specialists
- Advanced nurse practitioners
 - Advancing roles
 - Expanding skills
- Nurse Consultant
 - 50% clinical, 50% research / service development/ education



Clinical Nurse Specialist roles





Clinical Nurse Specialist roles

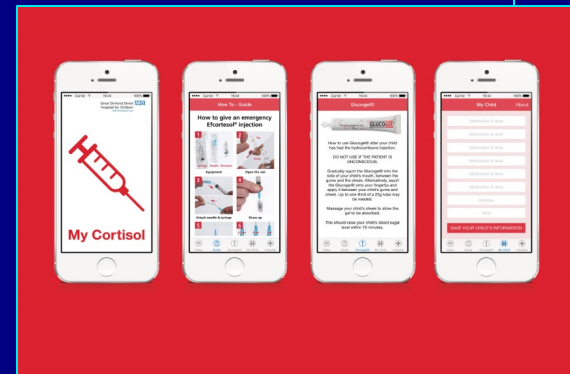
- Clinical Expert

- Clinical knowledge
- How can your knowledge and skills within endocrinology be enhanced

- ? Further training / development

- Education

- Sub-role as Educator
 - Patients, families, staff
- Evaluate and develop educational programmes
- Build teaching packages for patient education



Clinical Nurse Specialist roles

- Consultant

- Leading on case management
- Becoming more involved in external forums

- Society committees
- Patient support groups
- Advisory boards



- Research

- Identifying gaps within your clinical service which could use research / audit
 - Explore shortfalls / Positive aspects
- Patient questionnaires
- Participation in clinical research



Clinical Nurse Specialist roles

- Patient advocate

- Identify patient support groups not already utilised by your team
 - Develop and strengthen links
- Enhance existing relationships
- Develop own patient literature

- Collaborator

- Enhance collaboration within the MDT and interdisciplinary teams
 - Ensure common purpose
- Working with other endocrine nurses
- Pharmaceutical companies

Clinical Nurse Specialist roles

- **Leadership / Management**
 - Lead in developing and attaining team goals
 - Contribute to practice development
 - Develop patient care pathways
 - Sharing patient literature
- **Change Agent**
 - Provide evidence where CNS intervention could be useful
 - Nurse led clinics
 - Telephone clinics
 - Innovative practice



CNS as Change Agent

- Success of CNSs

- Depends on their ability to develop their own support system

- Generate own job satisfaction

- Motivation

- Increased high output

- Negotiation

- = Change!
 - Occurs at a slow pace
 - ? Cost

- Need evidence for need for change

- » ? Shortfalls in existing service

- » ? Decreased patient satisfaction



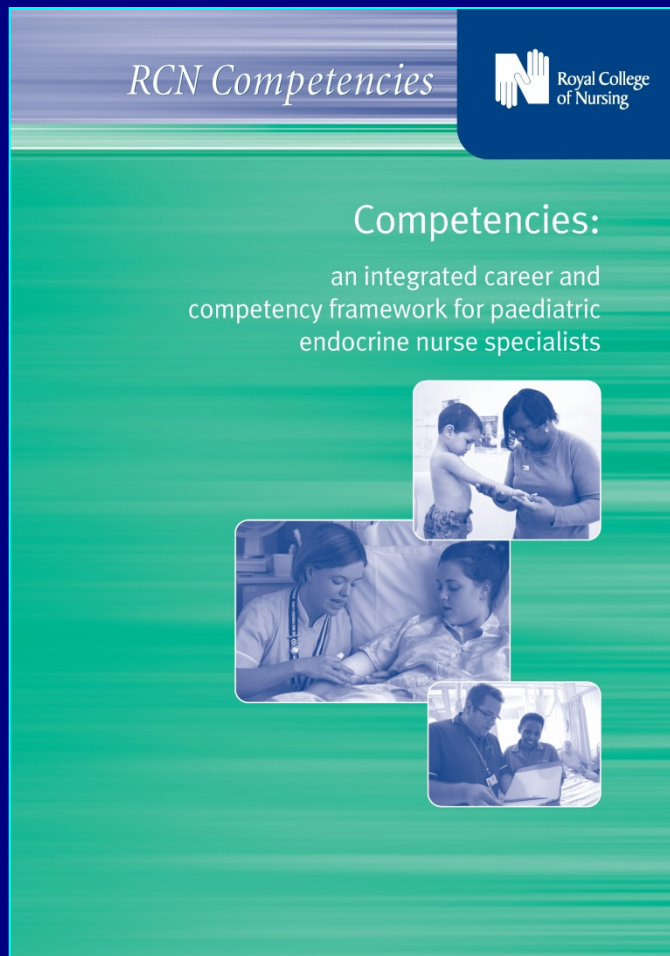
(Llahana, 2005)

Advancing CNS roles

- Using Change Agent concept
 - Back up what you do
 - Use this evidence to change practice
 - Utilise frameworks to provide the evidence
 - Explore educational pathways
 - See how nursing care can be advanced



Guidelines for practice



- Focus on knowledge, skills and interventions specific to endocrine nurses
- References local and national guidelines
- Adheres to Benner's (1982) 'Novice to Expert' concept
 - Competent practitioner
 - Experienced practitioner
 - Expert practitioner

Benefit to three groups

– Nurses

- Delivers high standards of care
- Identifies practice level
 - Plan career in a structured way
- Pinpoint personal educational needs
- Realise potential
- ***Seize opportunities to influence the direction of nursing***

– Employers

- A model for high care standards
- Clearer insight into staff competence
- Assistance in organisational planning

– Patients

- Provide high standards of care



Competencies

- During period where diagnosis is not yet reached
- Once diagnosis is confirmed
- Endocrine testing
- Transition
- Factors influencing growth
- Auxology
- Assessment of skeletal maturity
- Physiology and pathology

Education for advanced practice

- Post-graduate pathways
- BSc
- MSc
 - Children's Advanced Nurse Practitioner



Children's Advanced Nurse Practitioner

- 3 year MSc course
- Accredited by the RCN
- Specialising in specific fields



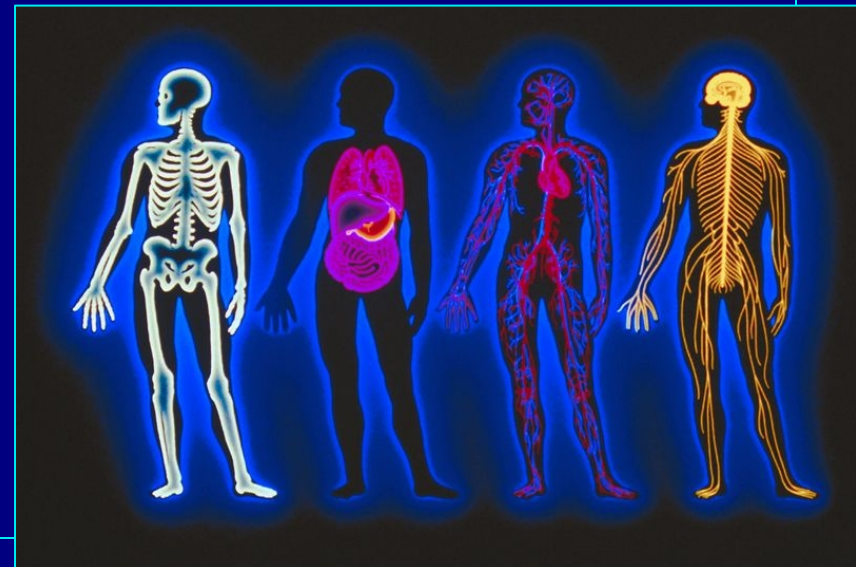


Course Content



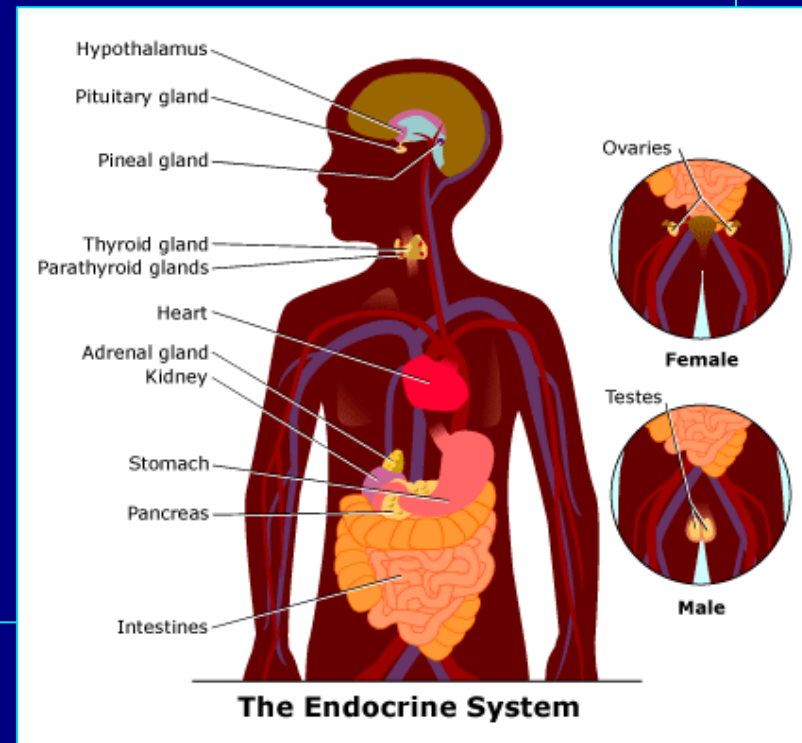
Advanced assessment

- History taking
- Examination of the infant, child and adolescent
- Physical assessment techniques
 - Inspection, palpation, percussion and auscultation
- Principles of anatomy, physiology and pathology
 - Respiratory and CXR interpretation
 - Cardiac
 - Neurological
 - Abdominal
 - Neonatal
 - Head, Eyes, Ear, Nose and Throat
 - Pain
 - Mental health
 - MSK
 - Growth and development



Applied physiology

- Brain development
- Management of raised ICP
- Endocrine physiology and growth and development
- Paediatric oncology
- The immune system
- Embryology
- Respiratory physiology
- The liver and metabolism
- Haematology
- Maturation of the renal system
- Physiology of the GI system



Non medical prescribing

- **Practical aspects of prescribing**

- Clinical portfolio
 - Practice log hours (75)
 - Reflection (650 words) on Domains:
 - The Consultation
 - Prescribing effectively
 - Prescribing in context
 - 72 competencies to achieve
 - Clinical management plan
 - Prescription

- **Prescribing in clinical practice**

- Clinical conditions
 - History taking and differentials
- Written case study (3500 words)
- OSCE
 - History taking and differential diagnosis

- **Pharmacology and applied therapeutics**

- Pharmacological management of common conditions in all body systems
 - Written exam
 - Drug calculation exam
 - OSCE
 - Omeprazole, paracetamol, salbutamol, simvastatin, hydrocortisone cream, amoxicillin



Managing the complex child

- Principles of A&P
- Physical examination
- Models of problem solving
- Clinical decision making
- Indications for referral / how to refer
- Pharmacological management
- Appropriate documentation of findings
- Managing clinical uncertainty and complexity



Furthering education in paediatric endocrinology

- Auxology course – St Bartholomew's and The Royal London Hospitals
 - Growth measurement
 - Bone age reading
 - Growth clinic
- BSc module – Keele University
- BSc/MSc module – London South Bank University



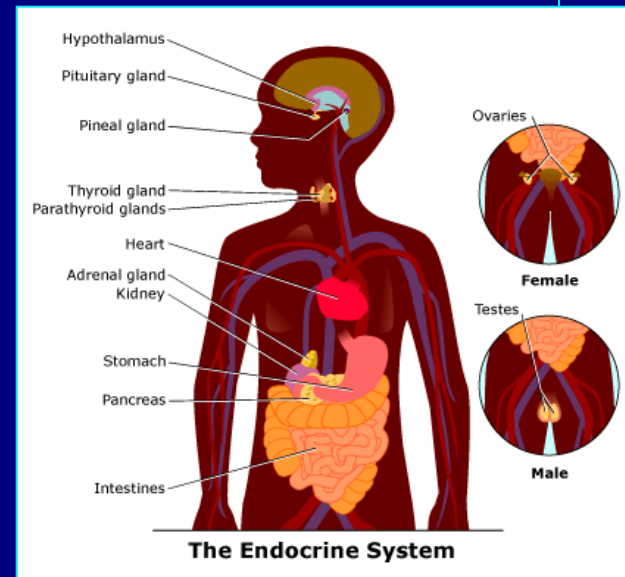
Principles of care of the child and young person in endocrinology*

- Practice-based assessment
 - Competency-based booklet
- Formative assessment
 - Group work
- Summative assessment
 - Case study presentation
 - BSPED approved
 - January 2017



Module content

- The endocrine system
- The multidisciplinary team
- Growth and the IGF-1 system
- Puberty
- Adrenal disorders
- Disorders of sex development
- Thyroid disorders
- Disorders of salt and water balance
- Pancreas disorders
- Bone metabolism and bone health
- Late effects of childhood cancers
- Hormone replacement treatment
- Advanced nursing roles in paediatric endocrinology



Assessment - 1

- Competency based booklet
 - Practice based assessment
 - Specific skills
 - Ward
 - Community
 - Based on RCN competency framework (2013)



Assessment - 2

- Formative assessment
 - Group work
 - Given scenario
 - Endocrine condition
 - Medical management
 - Pharmacological intervention
 - Nursing care
 - Feedback and present to the group at the end of the day



Assessment - 3

- 20 minute case study presentation
 - Module lead
 - Clinical expert
 - Examiner
- Patient of your choice
 - Demonstrating emphasis
 - Knowledge of endocrine condition
 - Pharmacological knowledge
 - Nursing care
 - Nursing intervention
 - Reflection



On completion..

- BSc in children's nursing
 - Old style training
- Pg Diploma in children's nursing
 - Already have a degree
- MSc in children's nursing
 - Clinical Nurse Specialist

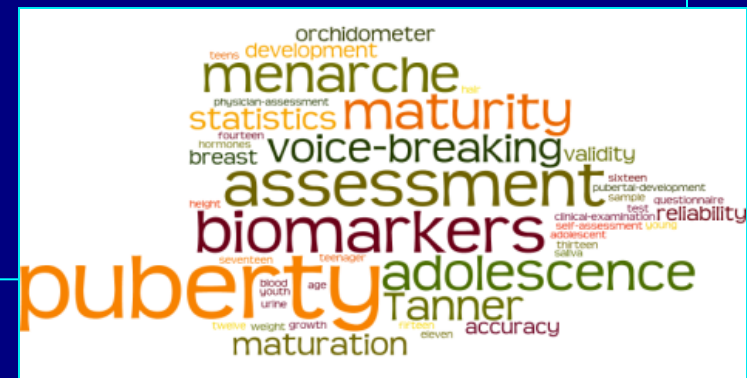
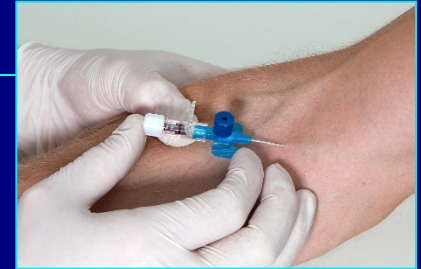


Paediatric endocrine nurse roles

- Patient education
- Patient / parent / family support
- Hands on nursing care
- Dynamic function tests
- Liaising / principle key worker within multidisciplinary team
- Liaising with community teams / General Practitioners
- Liaising with pharmaceutical industry
- Teaching
- Research

Advanced skills for paediatric endocrine nurses

- Practical skills
 - Venepuncture/cannulation
 - Dynamic function tests
 - Physical assessment
 - Bone age assessment
- Managing own patient caseload
- Nurse-led clinics



Nurse-led care

- Nurse-led clinics
 - Outpatients
 - Telephone
- Day care
 - Nurse led investigations
 - GH choice and training
 - Emergency hydrocortisone training



Nurse-led clinics

- **Aims:**
 - Decreases patients' waiting times
 - Including the nurse-led clinic
 - GH prescribing process
 - Increases consultants' time for more complex patients
 - Build stronger relationships with patients and their families
 - Enhances patient satisfaction
- **Documented evidence for multiple benefits of nurse-led clinics^{1,2}**



Nurse Led Clinic

- Aims

- To support intermediate care after the acute phase of disease and/or diagnosis
- Integrate patient into the care pathway
- Deliver holistic care
 - Person centered and evidence based
- Promote self care and enhance patient autonomy and concordance

Supporting the child and the family





Clinic 1

Nurse led general paediatric
endocrine clinic in a general
hospital – specialist centre



Aims of NLC



- Specific follow up for long term management
- More general patient education
- GH choice and start up
- Sick day management
- Patient education / compliance issues
- Alternate consultant appointments for less complex patients
- Precocious puberty management
- Appointment slots
 - 20 minutes
 - 40 minutes for new GH / sick day management training x2
 - 8 appointments in one clinic session



Growth Hormone prescribing process -

- Consultant decides to initiate GH →
 - Nurse Led clinic
 - Go through understanding of condition
 - Side effects / adverse events
 - Demo of GH devices
 - ? Indecisive
 - DVDs / literature
 - Family to call CNS back
 - Another appointment offered
- Consultant writes to GP asking them to prescribe GH under a shared care protocol – copy also to the parents
- Once have decision of GH device from family, CNS contacts appropriate homecare team with patient info
 - Community nurse goes to patient's home at a time convenient to them
 - Prescriptions through GP → homecare
 - Medication and equipment delivered to home
- GP discusses prescription with practice manager
 - Decides to prescribe or not
 - If no, prescribe from hospital → CCG
- Whole process
 - Approximately one month



Proformas for clinic

- CAH
- CPP
- Congenital hypothyroidism
- GH administration training
- GH choice
- IM HC training
- Panhypopituitarism

- Premature adrenarche
- Premature thelarche
- PWS
- Turners syndrome



Paediatric Endocrine Nurse Led Clinic: GH administration

proforma

Name: _____ DOB: _____ CA: _____
Hospital No: _____ Date: _____

Pre Clinic discussion

Nurse led consult:

Present:

Device:

Dose:

Demonstration given:

Patient / Carer demonstrated:

Reconstitution:

Administration:

Needle size:

Needle guard:

1 / 2 handed:

L / R handed:

Advice given:

Storage:

Change injection site:

Side effects:

Patient support group:

Customs letter given:

Any other issues:

Child / carer:

I am happy in preparation and giving the injection
and giving the injection
been given patient's concerns

Signed: _____

Relationship to child: _____

CNS Sign: _____

Paediatric Endocrine Nurse Led Clinic: Sick day management proforma

Name: _____ DOB: _____ CA: _____
Hospital No: _____ Date: _____

Pre Clinic discussion

Nurse led consultation

Present:

Copies of letter given:

Reason for management:

CAH:

Adrenal insufficiency:

~~Severe hypoglycaemia:~~

Medication given:

~~Hydrocortisone:~~

Glucagon: _____

Injection instructions given and demonstrated:

Patient / Carer demonstrated:

Information given sick day management:

Patient support group / literature:

Customs letter given:

Any other issues:

Parent / Carer:

I understand the sick day management
double or treble the dose of oral hydrocortisone
it. I know what to do if
an emergency injection of hydrocortisone
am aware of the symptoms of low
give an injection of glucagon if necessary
management plan and will produce if
needed.

Signed: _____

Relationship to child: _____

CNS Sign: _____

REVIEW

Paediatric Endocrine Nurse Led Clinic: CPP proforma

Name: _____ DOB: _____ CA: _____
Hospital No: _____ Date: _____

Pre Clinic discussion

Nurse led consultation

Height: _____ Weight: _____

Growth chart in notes and plotted: _____

Pubertal Assessment:

B					P					A					M				
1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	0/1				

Medication:

~~GoRH~~ agonist:

Given by:

Liaised with GP / community nurses

Body image:

Hygiene

Clothing

School:

Need for liaison?

Patient support:

Areas of concern for discussion:

Pubertal progression

Behavioural changes

Dramatic ↑ in height and weight

Coping ↕ Psychology:

Next review:

Age	Frequency	CNS	Cons
Any	6/12 normal review 3/12 if treatment given		

Signed: _____ Name: _____ Position: _____

Paediatric Endocrine Nurse Led Clinic: TS proforma

Name: _____ DOB: _____ CA: _____
Hospital No: _____ Date: _____

Pre Clinic discussion

Nurse led consultation

Height: _____ Weight: _____

Growth chart in notes and plotted: _____

TS Growth chart in notes and plotted: _____

Growth Hormone: Yes _____ No _____

Device: _____ Dose: _____ Compliance: _____

Injection sites: _____ Customs letter: _____

Homecare: _____ Latest IGF-1: Date: _____ Result: _____

Thyroxine: Yes _____ No _____ Compliance: _____

Latest TFT: Date: _____ TSH: _____ T4: _____

Oestrogen: Yes _____ No _____ Compliance: _____

Type: _____ Dose: _____

Multidisciplinary involvement:

Orthopaedics:

Cardiology:

Ophthalmology:

ENT:

School:

Transition discussion:

Patient support:

Bloods:

Today: _____

IGF-1 _____ TFTs _____

Areas of concern for discussion:

Growth failure

Lack of pubertal progression once on E2

Medication change

Coping ↕ Psychology:

Next review:

Age	Frequency	CNS	Cons
Any	6/12		

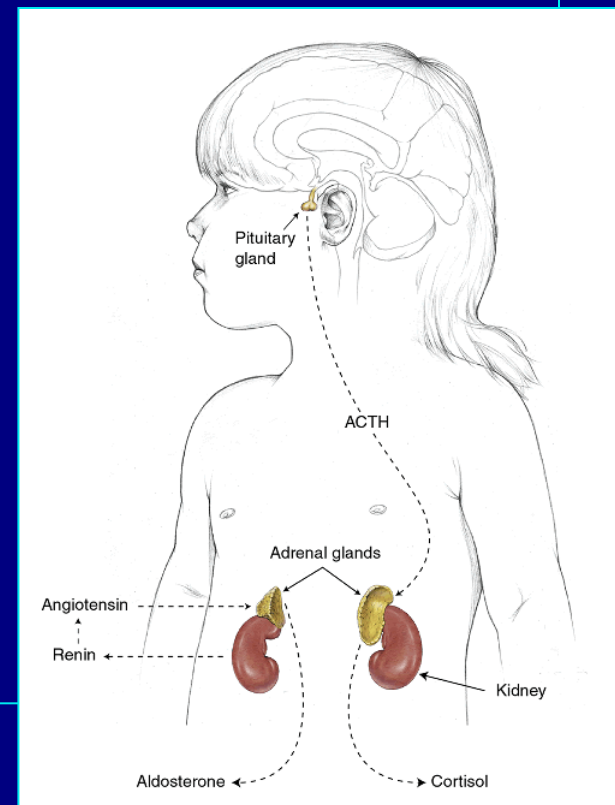
Signed: _____ Name: _____ Position: _____

Clinic 2

Nurse led adrenal clinic in a
paediatric tertiary hospital

Diagnosis of CAH

- Confirmed by a raised 17OHP level after day 3 of life
- Short synacthen test
- Urine steroid analysis
- Salt wasting confirmed by:
 - Low plasma sodium
 - High potassium
 - Increased urinary sodium excretion
 - Virilised girls
 - Chromosome analysis
 - Pelvic ultrasound



Medical management

- **Hydrocortisone 10mg tablets**
 - 10 – 15 mg/m²/day
 - Total dose spread 3 – 4 times throughout the day
- **Fludrocortisone 100 mcg tablets**
 - 150 mcg / m²/ day
- **Salt supplements**
 - Oral salt supplements (until one year of age) in the 5mmol/ml 30% Sodium Chloride solution – 5mmols/kg/day, in 4 divided doses =mls per dose four times a day
 - Can stop when fully weaned

Holistic management

Education

Resources

Safety at home



Great Ormond Street

GP details

Date

Dear Dr

RE:

Diagnosis: Congenital

..... was referred to
Hyperplasia has been

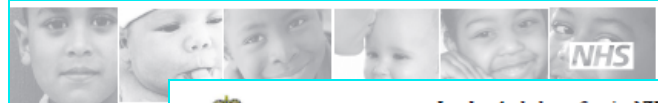
She/he has been com
commence a repeat p

Hydrocortisone
Fludrocortisone
Oral salt supplements
5mmols/kg/day, in 4 c

Also to be included on
Hydrocortisone Emerg
Efcortisol 100mg vials
Glucose Gel 25g tube,

We have given
prepare and administe
during times of illness
the need arise, along v
Medic Alert jewellery

We have arranged wit
should he/she require
.....Ambulance Service



Great Ormond Street

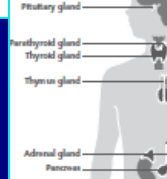
Cortisol deficiency steroid replacement

This leaflet explains a
how it is treated. It al
how to deal with illne
stressful events in chi

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We have arranged wit
should he/she require
.....Ambulance Service



London Ambulance Service NHS Trust

Patient Specific Protocol

This protocol has been

Patient's Name:

NHS Number:

Address:

School:-

Local hospital:

Reason for protocol:

Specific Treatment
administered in an em

In the event that this c
any symptoms of a ste
hydrocortisone as deta

Note:- The IM hydroc
pack.

Please transport this c
unit.

All other aspects of cl

**For further advice if
Great Ormond Street**

1. Efcortisol 1ml ampou
Dose: Age 0-1 years 25
Age 1-5 years 50mg
Age 5+ years 100mg

2. Please also administe
already previously admin

Following administration
required.

All other aspects of clin

If required contact EO

PTO for further genera

Great Or
Hospital

Gastroenterology, Endocrinology, Metab

Re:

Diagnosis:

Medications: Hydrocortisone (oral)

Fludrocortisone (oral)

NaCl supplements 5mmol/ml 30% solution:

Instructions for Hospital Doctor

In view of this patients cortisol deficiency, if this patient is brought to hospital the following management is advised:

- If patient drowsy and unresponsive give IM hydrocortisone immediately (0-1yr – 25mgs; 1-5 yrs – 50mgs; > 5yrs – had IM hydrocortisone administered by ambulance crew)
- Take blood for U&Es, glucose and osmolality
- If blood glucose is < 2.5 mmol, give bolus of 2mg/kg 10
- If patient is drowsy, hypotensive and peripherally shut down insert an IV cannula and then continue with usual dextrose saline infusion
- Continue with bolus IV hydrocortisone at 2mg/kg every 4 hours until patient is tolerating oral fluids and then swap to double usual oral Hydrocortisone doses until patient fully recovered and back to normal self (usually 2-3 days on double usual hydrocortisone doses).
- **Important:** Please admit for a minimum of 12 hours

If there is any doubt about this patients management, advice can be obtained via Great Ormond Street Hospital switchboard (0207 405 9200, asking for the Endocrine Registrar on Call).

Great Ormond Street **NHS**
Hospital for Children
NHS Foundation Trust



My Cortisol

Adrenal nurse led clinic

- First appointment
 - One month after diagnosis / discharge from hospital
 - Discuss
 - Compliance
 - Management of medication
 - Re-educate sick day and emergency management
 - Teach injection technique
 - Follow up on any queries the family have
 - Liaise with Urology if female
 - Liaise with local teams for recent blood results
 - Discuss patient support groups

Adrenal nurse led clinic

- Subsequent appointments...
 - Alternate clinic appointments with medical consultations
 - Compliance issues
 - Re-education
 - Any prescription problems
 - Hydrocortisone tablets
 - Salt supplements
 - Emergency hydrocortisone
 - Arranging annual reviews in readiness for medical appointment
 - 24 hr profile
 - Bone age
 - Clinical examination for under / over dosing of hydrocortisone
 - Transition discussions
 - → Transfer for adolescence

Professional Issues

- Non medical prescribing course
 - Case study – Infant with CAH
 - Bioequivalence of hydrocortisone tablets and suspension (Merke, 2001)
- Led on to further modules:
 - Advanced assessment of the presenting child
 - Children's Advanced Nurse Practitioner

- Continuing CPD

Nurse Led Clinics

- Managerial support

- Huge issue
- **Positive**
- Increase revenue into the hospital
- Increased profile of nursing expertise / department
- **Negative**
- Room
- Admin
- Support
- Team issues

- Team support

- Smooth liaison between medical and nursing personnel
 - Consultants and junior Doctors

Conclusion

- Focus
 - Education
 - Advanced Practice
 - Nurse led clinics
- Varied roles
 - Paediatrics
 - Adults
 - Internationally

