The Clinical Nurse Specialist role in the DSD service in London, United Kingdom

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Great Ormond Street Hospital for Children NHS Trust
Conflict of Interest Disclosure

- Paediatric Endocrine Nurse Advisory boards – UK
  - Ipsen Ltd
  - Ferring Pharmaceuticals
  - Sandoz

- Invited lectures at Pharmaceutical company meetings
  - Ferring pharmaceuticals
  - Merck Serono
  - Novo Nordisk
  - Pfizer
  - Sandoz

- Winner of Ipsen BSPED Paediatric Endocrine Nurse Award 2014
Introduction

• Objectives
• Geography
• The British National Health Service system
• What is a DSD?
• Our DSD team and service
• Referrals to GOSH
• The team role
• The CNS role
  • DSD
  • Adrenal
• Conclusion
• References
Objectives

• Describe the referral process for a baby with a DSD within the British National Health Service (NHS)

• Discuss the Great Ormond Street Hospital for children diagnostic flow chart

• Identify the role of the Clinical Nurse Specialist (CNS) in the DSD multi-disciplinary team
Geography and statistics
Relative sizes and population

- Most of England, Scotland and Wales covering most of Missouri and Iowa
  - Missouri: 6.1 million
  - Iowa: 3.1 million

- UK population: 64.1 million

- USA population: 318.9 million

- London population: 8.6 million
  - Los Angeles: 10 million
United Kingdom
LONDON
- Capital of England
- Founded 43 AD
- 606 square miles
  - 1.2 square miles City
- Over 300 languages spoken
- Underground tube system
  - oldest in the world
Great Ormond Street Hospital for Children

- Opened in 1852
- Patroned
  - Queen Victoria → Princess Diana
  - Charles Dickens
  - JM Barrie – Peter Pan
- 387 patient beds
- > 50 clinical specialities
- > 240,000 patient visits per year
- 50% patients come from outside London
- Tertiary hospital
  - No ER
The British National Health System

• Formed in 1948 to provide free healthcare for all
  • Antenatal, maternity, postnatal, immunisations, child health, screening, ER

• Primary healthcare
  • General Practitioners, Practice Nurses, Health Visitors, School Nurses
  • Day to day healthcare

• Secondary healthcare
  • Provided by medical specialists – ‘hospital care’
  • Referrals made by the patient’s GP

• Tertiary healthcare
  • More highly specialised healthcare
  • Referral made by a secondary healthcare professional
What is a DSD?

- Congenital conditions in which development of chromosomal, gonadal or anatomic sex is atypical
- True genital ambiguity
  - 1 in 5000 / 1 in 4500 births
- Genital anomalies
  - 1 in 300 births
Classification of DSD

• 46,XY DSD (under virilised genetic male)
  • Disorders of testicular development
    • Ovotesticular DSD
  • Disorders of androgen synthesis / action
    • CAIS
  • Others
    • Hypospadias

• 46,XX DSD (over virilised genetic female)
  • Disorders of ovarian development
    • Ovotesticular DSD
  • Androgen excess
    • CAH

• Sex chromosome DSD (variable)
  • Turner’s syndrome
  • Klinefelter’s syndrome
  • Mixed gonadal dysgenesis
<table>
<thead>
<tr>
<th>Sex Chromosome DSD</th>
<th>DSD 46,XY</th>
<th>DSD 46,XX</th>
</tr>
</thead>
</table>
| 45,X (Turner Syndrome and variants) | Disorders of gonadal (testicular) development:  
1) Complete gonadal dysgenesis  
(Swayer Syndrome)  
2) Partial gonadal dysgenesis  
3) Gonadal regression  
4) Ovotesticular DSD  
5) CBX2 gene def. (ovaries + fem. ext. gen.) | Disorders of gonadal (ovarian) development:  
1) Ovotesticular DSD  
2) Testicular DSD (SRY**, duplication of SOX9), 46,XX males. Def gen  
3) Gonadal dysgenesis |
| 47,XXY (Klinefelter Syndrome and variants) | Disorders of androgen synthesis or action:  
1) Androgen biosynthesis defects (17-hydroxylase, 5αRD2, 3αβHSD, 17β-HSD)  
2) Defects in androgen actions (CAIS, PAIS)  
3) Defects in LH receptor (Leydig cell hypoplasia)  
4) Defects in AMH or AMH receptor (Persistence Mullerian ducts syndrome) | Androgen excess:  
1) Fetal (Defects in 21-hydroxylase, or 11-hydroxylase)  
2) Fetoplaental (deficiencia de aromatasa, POR [P450 oxidoreductasa])  
3) Maternal (luteoma, exogenous androgens, etc) |
| 45,XY/46,XY (mixed gonadal dysgenesis, ovotesticular DSD) | Other (cloacal extrophy, severe hypospadias) | Other (cloacal extrophy, vaginal atresia, other) |
| 46,XX/46,XY (chimeric, ovotesticular DSD) | | |
**Revised nomenclature: Chicago Consensus 2006**

<table>
<thead>
<tr>
<th>Previous</th>
<th>Revised</th>
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<tbody>
<tr>
<td>Intersex</td>
<td>Disorders of sex development (DSDs)</td>
</tr>
<tr>
<td>Male pseudohermaphrodite</td>
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<tr>
<td>Undervirilization of an XY male</td>
<td>46,XY DSD</td>
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<td>Undermasculinization of an XY male</td>
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<tr>
<td>Female pseudohermaphrodite</td>
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<td>Overvirilization of an XX female</td>
<td>46,XX DSD</td>
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<td>Masculinization of an XX female</td>
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<tr>
<td>True hermaphrodite</td>
<td>Ovotesticular DSD</td>
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<td>XX male or XX sex reversal</td>
<td>46,XX testicular DSD</td>
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<tr>
<td>XY sex reversal</td>
<td>46,XY complete gonadal dysgenesis</td>
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DSD MDT team at GOSH

Endocrinologist
Urologist
Psychologist
CNS

Biochemist
Pathologist & Histopathologist
Imaging & Urodynamics
Gynaecologist
Reproductive medicine

Local Paediatrician +/- Surgeon / Urologist +/- Midwives / Nurses
Clinical & Molecular genetics
General Practitioner & Social Work
Community and Religious Leaders
Ethicist
Endocrine CNS team

- Congenital Hypothyroidism
- Congenital Hyperinsulinism
- Neuro Endocrine Oncology
- Hypopituitarism / Septo-Optic Dysplasia
- Adrenal / DSD
Clinical actions – UK approach (Ahmed, 2011)
Monthly MDT meeting

• Every 2\textsuperscript{nd} Monday of the month
• All meet
  • Lead Consultant Endocrinologist with DSD interest chairs the meeting
  • Registrars (Residents) present new cases
    • Discuss previous cases
      • Attended outpatients clinic
      • Attended the endocrine day case unit (Kingfisher)
      • Had EUA (Woodpecker)
      • Had surgery (Squirrel)
  • CNS
    • Makes notes on planned outcomes and proposed interventions.
      • CNS team ipad
      • Emailed to relevant people with tasks to be done
CNS DSD MDT notes

<table>
<thead>
<tr>
<th>Name</th>
<th>Hosp No</th>
<th>Cons</th>
<th>Referring Hosp</th>
<th>Diagnosis</th>
<th>Plan</th>
<th>Action</th>
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GOSH DSD diagnosis statistics - 2014

- 53 new referrals over one year
- Averaging 6 a month
DSD referral areas
DSD ages of referral at GOSH

- **Infants**
  - Usually present with atypical genitalia

- **Adolescents**
  - Atypical sexual development
    - Micropenis
    - Cryptorchidism
    - Referrals from other centres
      - Previous hypospadias surgeries
      - Familial atypical genitalia
      - CAIS
GOSH DSD data over 21 years N= 657
### Other – 38 single diagnoses

<table>
<thead>
<tr>
<th>Conditions</th>
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<tbody>
<tr>
<td>Kallmann’s syndrome</td>
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<tr>
<td>IMAGE syndrome</td>
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<tr>
<td>Labial fusion</td>
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<tr>
<td>Accessory phallus</td>
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<tr>
<td>Clitoral hypertrophy</td>
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<tr>
<td>Absent vagina / ovary</td>
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<tr>
<td>Atrophic right testes</td>
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<tr>
<td>WAGR syndrome</td>
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<tr>
<td>Tumours</td>
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<tr>
<td>CHARGE syndrome</td>
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<tr>
<td>Testicular tumour</td>
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<tr>
<td>Duplicated genitalia</td>
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<tr>
<td>Aphalia</td>
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<tr>
<td>Delayed / precocious puberty</td>
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<tr>
<td>SOX2, SOX9</td>
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<tr>
<td>Smith – Lemli – Opitz</td>
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<tr>
<td>Meacham syndrome</td>
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<tr>
<td>Lipoid CAH</td>
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</table>
How we get a referral

- On call registrar receives a telephone call from referring Doctor from another hospital
- Alerts main DSD team
- Plan admission
  - Within 5 days if newborn
- Asks referring Dr to undertake specific investigations
- Plans investigations
  - Pelvic ultrasound, medical photography
- Clinical Nurse Specialist
DSD referral form

- Emailed to lead consultant
- Filed in patient notes
- Filed in DSD file
CNS role for new admission

- Ensure referring team has parents admission leaflet
- Ensure Registrar has completed referral form
- Liaise with:
  - Consultant Endocrinologist
  - Psychologist
  - Consultant Urologist
  - Sister and admissions team on Kingfisher ward
  - PARENTS!
    - Admissions leaflet from GOSH website (under review)
- Set a date and time for one day admission
It’s the little things..

- **How is the baby feeding**
  - Breast pump, bottles, quiet area available
  - Bottle feeding – enough milk

- **Ensure parents bring**
  - Phone chargers, nappies, wipes, books etc, lists of questions
  - Maternity notes, child health care notes, referral letters
  - Money for parking

- **Can they speak English**
  - Arrange interpreter, prepare translated information

- **Transport / nurse escort**
  - Liaise with NICU / Respiratory ward (Badger)

- **Ensure GnRH, Synacthen and HCG in stock on ward if need be**

- **Prepare information packs for parents**
  - DSD families leaflet
  - Cortisol deficiency booklets
  - CAH information
  - CNS business card / contact details
DSD families leaflet

- dsdfamilies.org
- UK based support group
  - Information and support resource for families with children, teens and young adults with a DSD
  - Links to other support groups throughout the UK
    - CAH, TS, Hypospadias, Klinefelter, AIS
  - Links to international DSD support groups
GOSH Diagnostic flow chart
INFO TO ASK

**Patient details:** Name, DOB, gestational age, if parents speak English

**History:** Antenatal scans, presentation at birth, genital appearance (phallosize, gonads palpable, hyperpigmentation, scrotalisation or fusion of labia, urethral meatus position, hypospadias or chordee, anal position), dysmorphic features, feeding

**Family history:** Ethnic background, consanguinity, history of DSD

**Discussion with parents:** If sex has been assigned and parents expectations and worries

**Clinical status:** If baby well, if ventilated or other medical issues (e.g. antibiotics)

**Investigations:** What has been sent and current U&E, any imaging that has been done (caution)

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Dr rang by external hospital for baby with atypical genitalia
INFO TO GIVE

**PLEASE ASK FOR SEX ASSIGNMENT TO BE DELAYED UNTIL DSD TEAM ASSESSMENT**

Get the local team to arrange urgent FISH or qPCR – they need to speak to the lab so initial results are obtained within 24-48 hours. Full karyotype/array CGH to be sent and prioritised, incl mosaic screen. (Please inform us of the genetics centre so we can communicate with them directly if needed)

Monitor: Daily U&E, blood glucose (esp if poor feeding), BP & urinary sodium if sodium falling After day 3: ACTH and cortisol, USP, 17OHP and discuss further tests if baby not seen by then; check for proteinuria

Download information leaflet from GOSH website for local team and family (web site page here)
Send DSD families brochure by pdf, hard copy or download from website (www.dsdfamilies.org)
Offer the parents an opportunity to talk to a member of our DSD team for support.

Arrange for day review urgently on Kingfisher; we need referral letter faxed with details, GP etc
DISCUSS WITH ENDOCRINE CONSULTANT ON CALL AS THEY ARE THE NAMED CLINICAL LEAD
HOW TO ARRANGE DAY ADMISSION:

People to liaise with:
- Kingfisher admissions and Carly Hadfield (sister on KF) – Specify this is a DSD baby (Request Treatment Room and have consulting room available; may need bed)
- Get the baby registered
- Endocrine Consultant on call and Urology (usually Mr Imran Mushtaq or Ms Naima Smeulders) to arrange when they are available to assess baby
- Professor John Achermann
- DSD nurse (Kate Davies – email)
- Dr Polly Carmichael (Clinical psychologist)
- cc All Endo Regs
- NICU if needed – in rare circumstances
- Get the baby registered

Enquire about transport/nurse escort, and ensure baby not incubator dependent
Ensure LHRH, Synacthen and hCG in stock on ward
Organise interpreter if needed
Breast pump and bottles / bottles of milk on Kingfisher
Inform parents they will meet several people and be prepared for long day (drinks, nappies)
Add name to DSD MDT list
To ARRANGE:
- Pelvic and abdominal (renal) USS
- Clinical photography (if parents consent)
- General Bloods: U&E, Cortisol, ACTH, testosterone, inhibin B and AMH, FSH and LH
- USP (if not done or as back up sample); urinalysis for proteinuria (if not done)
- Bloods for DNA storage (if parents consent)
- Consider other investigations as required (e.g. synacthen test, LHRH test, PRA, aldosterone, prolactin/TFTs/IGF1)
- Cancel tests if samples not necessary (e.g. AMH in CAH) or duplicated (e.g. USP being done)

ON ADMISSION “MEET AND GREET” THE PARENTS, EXPLAIN WHAT WILL HAPPEN AND WHO THEY WILL SEE, AND FOCUS ON SUPPORT AS WELL AS THE PLANNED “TESTS” – appreciate how tired and stressed they are, and maintain their privacy; let them have time together to talk and reflect

46,XX
If CAH suspected (common):
PRIOR TO TREATMENT: Cortisol, PRA, Aldosterone, 17-OHP, A4, DHEAS, 11-deoxycortisol, USP
Short synacthen test only after day 3

Ovotesticular DSD (rare):
AMH, inhibin B, testosterone, consider early EUA and laparoscopy

Aromatase deficiency (v rare); also clitoromegaly of prematurity and structural variants

45,X/46,XY
AMH, inhibin B, testosterone, LH/FSH;
Consider 3 day/3 week hCG stimulation test or early EAU/laparoscopy;
ECHO, TFTs, renal USS, Turner screening, audiology etc

46,XY
Ensure adrenal function adequate (rare):
ACTH, cortisol, synacthen
Is it dysgenesis, steroidogenic defect or androgen resistance?
AMH, inhibin B, testosterone, LH/FSH, USP;
Consider 3 day/3 week hCG stimulation test
On the day

- Parents and child come to Kingfisher ward
- CNS greets family
  - Shows them their room
  - Ensures comfort, privacy
  - Explains procedures
- MDT appointments may be spread out
- CNS
  - Answer questions
  - Works with Registrar
  - Clinical examination
  - Weight, length, observations etc
On discharge..

- Template discharge letter
- Given to family at end of day
  - Details MDT meeting
  - Decision re sex of rearing
  - Investigations carried out
  - Differential diagnoses
- If CAH
  - Appt for adrenal NLC 1/12 later
  - Liaise with local hospital, nursery, community nurses, ambulance services..
Congenital adrenal hyperplasia (CAH)

This information sheet from Great Ormond Street Hospital (GOSH) explains about the medical condition congenital adrenal hyperplasia (CAH) and what to expect when your child comes to GOSH for assessment and treatment.

Congenital adrenal hyperplasia is a group of inherited conditions that are present at birth (congenital) where the adrenal gland is larger than usual (hyperplasia). In CAH, the body is missing an enzyme (chemical substance) that stimulates the adrenal glands to release the cortisol hormone. Lacking this hormone means that the body is less able to cope with stress, either emotionally or physically, which can be life threatening. It also makes the level of androgen (male hormone) increase, which causes male characteristics to appear early in boys or inappropriately in girls.

The adrenal glands rest on the tops of the kidneys. They are part of the endocrine system, which organizes the release of hormones within the body. Hormones are chemical messengers that switch on and off processes within the body.

The adrenal glands consist of two parts:

- the medulla (inner section) which makes the hormone ‘adrenaline’ which is part of the ‘fight or flight’ response a person has when stressed. This is not usually affected in CAH.
Dear Dr,

Diagnosis: Congenital Adrenal Hyperplasia

 was referred to us from Hospital, and a diagnosis of Congenital Adrenal Hyperplasia has been made, and s/he has cortisol deficiency.

He/she has been commenced on the following medication and we would be very grateful if you could commence a repeat prescription for:

- Hydrocortisone mg (as Hydrocortisone 10mg tablets, NOT suspension)
- Fludrocortisone mcg daily

Oral salt supplements (until one year of age) in the 5mmol/ml 30% Sodium Chloride solution – 5mmols/kg/day, in 4 divided doses = ml per dose four times a day

Also to be included on his/her prescription:
- Hydrocortisone Emergency Pack to be renewed yearly,
- Efectorol 100mg vials, 25/50/100mg to be given IM in an emergency.
- Glucose Gel 25g tube, 1/3 tube orally to be given in an emergency.

We have given ’s parents a tablet cutter and a tablet crusher, and have educated them in how to prepare and administer their medication. ’s parents have had education in his/her management during times of illness and they have been trained in giving IM hydrocortisone, 25/50/100mg, should the need arise, along with oral glucose gel. A steroid card has been given, and also information about Medic Alert jewellery to start wearing as soon as possible.

We have arranged with the local hospital and the local Paediatrician ( ) to have fast track access should he/she require emergency IM hydrocortisone. We have also set up an arrangement with Ambulance Service to ensure a red alert system is in place.

GP details

Date

RE:

• Medication onto repeat prescription system

• Tablets not suspension

• Also highlights that the baby can have all of their usual childhood immunisations
Sick day and emergency management

- Doubling up on hydrocortisone when unwell
- Additional 4am dose (same as morning dose)
Sick day and emergency management

- Emergency injection of hydrocortisone and oral glucogel
- Liaise with nurseries
  - Schools when older
- Medic alert jewellery
- Usually dispense x2 emergency packs
  - Home
  - Bag
    - Another when older for nursery/school
Emergency services

- Contact details for all UK ambulance services
- Red flag system
Great Ormond Street Hospital for Children
NHS Trust

Re:
Diagnosis: Hydrocortisone (oral)
Fludrocortisone (oral)
NaCl supplement 5mmol/ml 30% solution:

Instructions for Hospital Doctor

In view of this patient's cortisol deficiency, if this patient is brought to hospital as an emergency, the following management is advised:

- If patient drowsy and unresponsive give IM hydrocortisone in the following doses immediately (0-1yr – 25mg; 1-5 yrs – 50mg; > 5yrs – 100mg) if patient has not already had IM hydrocortisone administered by ambulance crew or parents.
- Take blood for U&Es, glucose and osmolality
- If blood glucose is < 2.5 mmol, give bolus of 2mg/kg 10% dextrose
- If patient is drowsy, hypotensive and peripherally shut down, give 20ml/kg of normal saline, 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 patient's management, advice can be obtained via Great Ormond Street Hospital switchboard (0207 405 9200, asking for the Endocrine Registrar on Call).
My Cortisol App
How to give an emergency Efcortesol® injection

1. Syringe
2. Needles
3. Efcortesol
4. Equipment
5. Attach needle & syringe
6. Open the vial
7. Draw up

How to use Glucogel®

DO NOT USE IF THE PATIENT IS UNCONSCIOUS.

Gradually squirt the Glucogel® into the side of your child’s mouth, between the gums and the cheek. Alternatively, squirt the Glucogel® onto your fingertip and apply it between your child’s gums and cheek. Up to one-third of a 25g tube may be needed.

Massage your child’s cheek to allow the gel to be absorbed.

This should raise your child’s blood sugar level within 10 minutes.

Touch to play video

Once you have given your child the medication please tap below to call 999 and state your child is having an ADRENAL CRISIS

CALL 999
Instructions for Hospital Doctor

Dear Doctor,
If this patient is brought to hospital as an emergency the following management is advised:
1) Insert an IV cannula
2) Take blood for U&Es, glucose, and perform any other appropriate tests (e.g. urine culture)
3) Check capillary blood glucose level
4) Give 100 mg hydrocortisone intravenously as bolus (unnecessary if patient has already been given IM hydrocortisone)
5) Commence IV infusion of 0.45% sodium chloride and 5% glucose at maintenance rate (extra if patient is dehydrated). Add potassium depending on electrolyte
6) Commence hydrocortisone infusion (50 mg hydrocortisone in 50ml 0.9% sodium chloride via syringe pump)
7) Monitor for at least twelve hours before discharge

IMPORTANT! If blood glucose is < 2.5 mmol/l, give bolus of 2 ml/kg of 10% glucose
If patient is drowsy, hypotensive and peripherally shut down with poor capillary return give 20ml/kg of 0.9% sodium chloride stat.

If in any doubt about this patient’s management, please contact the urgent advice numbers

Useful Contact Numbers:

GOSH Switchboard
Tel: 020 7405 9200

For Urgent Advice:
Tel: 020 7405 9200 and ask to be put through to the endocrine registrar on call

University College Hospital Switchboard
Tel: 0845 155 5000

For Urgent Advice:
Tel: 0845 155 5000 and ask to be put through to the endocrine registrar on call

CORTISOL DEFICIENCY
THE OWNER OF THIS CARD IS ON CORTISOL REPLACEMENT THERAPY

Name:
Address:
Date of Birth:
Consultant:
Hospital:
Tel:
Fax:

If any questions about this patient’s management, please contact the urgently advice numbers

Great Ormond Street Hospital for Children NHS Trust and
University College London Hospitals NHS Foundation Trust
Primary Care

• Open access onto local paediatric ward
• Contact details for all UK childrens’ community nursing teams
• Medical team to liaise with local medical team to arrange formal shared care plan
Primary care – blood levels

- Liaise with local teams for community nurses to visit family and take regular bloods for U&E
- Ensure results are fed back to GOSH
Adrenal nurse led clinic

• First appointment
  • One month after diagnosis / discharge from GOSH
  • 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
CNS Roles

- **Hamric & Spross (1989):**
  - **Consultant**
    - CNS as a resource or a consultant
  - **Educator**
    - Educating staff in disease specifics
    - Educating patients in self-care management
  - **Researcher**
    - Involvement in clinical trials
    - CNS’s own research related to nursing policy and practice
  - **Collaborator**
    - Importance of MD teamwork
  - **Leader**
    - Leadership and management

- **Change agent (Miller, 1995)**
- **Advocate (Miller, 1995)**
- **Liaison (Gibson and Bamford, 2001)**
- **Communicator-Carer (McCreadie, 2001)**
- **Entrepreneurs (Austin, 2006)**
  - Visualising how clinical services should function
### Clinical Nurse Specialist Roles

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<tr>
<th><strong>Clinical Expert</strong></th>
<th><strong>Consultant</strong></th>
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| • How can your knowledge and skills within endocrinology be enhanced  
  • Further training / development | • Leading on case management  
  • Becoming more involved in external forums  
  • Advisory boards, society committees |

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<tr>
<th><strong>Education</strong></th>
<th><strong>Patient advocate</strong></th>
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| • Sub role as Educator  
  • Patients, families, staff  
  • Evaluate and develop educational programmes  
  • Build teaching packages for patient education  
  • Eg IM HC, GH devices, puberty | • Identify patient support groups not already utilised by your team  
  • Develop and strengthen links  
  • Develop own patient literature |
Clinical Nurse Specialist Roles

**Research**
- Identify gaps in your service which could use research / audit to prove shortfalls
  - Or even *positive* aspects
- Patient questionnaires
  - Satisfaction in patient pathways

**Collaborator**
- Enhance collaboration within the MDT and interdisciplinary
  - Ensure common purpose
- Build and develop relationships with outside personnel

**Leadership / Management**
- Lead in developing and attaining team goals
  - Contribute to practice development
  - Develop patient care pathways
    - Patient literature

**Change Agent**
- Provide evidence where CNS intervention could be useful
  - Nurse led clinics
  - Telephone clinics
- Suggest, develop and implement business plans
Specifics..

- Making notes in MDT meeting
  - Ensuring full follow up
- Maintaining DSD database
- Consent forms for research
- Maintaining referrals folder and spreadsheets
- Arranging admissions
- Creating pathways, protocols and information sheets
- Teaching
- Presenting / lecturing
- There for the family on the day
- Support when discharged
- Liaison with Psychology – support group days
In conclusion

• Complex but quick overview of the DSD service in London
• Brief explanation of what a DSD is
  • Types of referrals we receive
  • MDT management
• Clinical Nurse Specialist role
  • Liaison
  • Organisation
    • Specifics of the role
• Future for more advanced nursing roles?
  • Further training
  • Principle point of contact for new DSD referrals

“Elves and nurses do have something in common. We do all the work and one guy in an over-sized coat gets all the credit.”
Thank you
References