NOTTINGHAMSHIRE AREA PRESCRIBING COMMITTEE SHARED CARE PROTOCOL AGREEMENT

Management of Growth Failure in Children and Young People with GROWTH HORMONE (Somatropin)

OBJECTIVES

- **Define the referral procedure from hospital to Primary Care and vice versa.**
- **Define the support available from the Nottingham Growth Service.**
- **Provide a summary of information on Growth Hormone therapy.**

REFERRAL CRITERIA

- Prescribing responsibility will only be transferred when it is agreed by the specialist and the patient's primary care prescriber that the patient's condition is stable.

REFERRAL PROCESS

- The request for shared care should include individual patient information, outlining all relevant aspects of the patient's care and which includes direction to the information sheets at www.nottsapc.nhs.uk.

- If the GP does not agree to share care for the patient then they will inform the Specialist of his/her decision in writing within 14 days.

- In cases where shared care arrangements are not in place, or where problems have arisen within the agreement and patient care may be affected, the responsibility for the patient's management including prescribing reverts back to the specialist.

BACKGROUND INFORMATION AND SCOPE

GPs, in association with other health professionals, identify children with short stature and/or low growth rates. These children are initially assessed within primary and community health teams for familial, general health and environmental factors that may restrict growth. The Nottingham Growth Service based at Queen's Medical Centre provides a resource for specialised growth review and identification of children likely to be candidates for Growth Hormone (GH) treatment.

Children with acquired GH deficiency as the result of brain tumours or cranial irradiation account for a significant proportion of GH therapy. Others have congenital multiple pituitary hormone deficiency, isolated idiopathic growth hormone deficiency or insufficiency.

Young people seen by members of the Nottingham Paediatric Growth Service will be retested at final height to see if they fulfil the adult growth hormone eligibility criteria as per NICE TA 64. Those needing to continue with growth hormone will be referred to the appropriate adult endocrinology service for their ongoing care.

CONDITION TO BE TREATED

As per NICE TA 188: Growth hormone deficiency, Turner syndrome, Prader-Willi syndrome (PWS), chronic renal insufficiency, born small for gestational age with subsequent growth failure at 4 years of age or later, short stature homeobox-containing gene (*SHOX*) deficiency.

AREAS OF RESPONSIBILITY

Specialists Roles and Responsibilities

1. The specialist will confirm the working diagnosis.
2. The specialist will recommend and initiate the treatment.
3. Where appropriate for new patients, the specialist will prescribe first line products in line with local recommendations.
4. The specialist will suggest that shared care may be appropriate for the patient's condition.
5. The specialist will ensure that the patient has an adequate supply of medication (usually 28 days) until shared care arrangements are in place. Further prescriptions will be issued if, for unseen reasons, arrangements for shared care are not in place at the end of 28 days. Patients should not be put in a position where they are unsure where to obtain supplies of their medication.
6. If shared care is considered appropriate for the patient, and the patient's treatment and condition are stable, the specialist will contact the GP.
7. The specialist will provide the patient's GP with the following information:
   - diagnosis of the patient's condition with the relevant clinical details.
   - details of the patient's treatment to date.
   - details of treatments to be undertaken by GP*.
   - details of all other treatments being received by the patient that are not included in shared care – e.g. analgesics, anti-TNFs etc
   - details of monitoring arrangements

   *Including reasons for choice of treatment, drug or drug combination, frequency of treatment (including day of the week if weekly treatment), number of months of treatment to be given before review by the consultant.
8. Whenever the specialist sees the patient, they will
   - send a written summary within 14 days to the patient's GP.
9. The specialist team will be able to provide training for primary care prescribers if necessary to support the shared care agreement.
10. Contact details for primary care prescribers during working and non- working hours will be made available
11. Details for fast-track referral will be supplied.
12. The specialist will ensure that the patient is monitored according to the Nottinghamshire Area Prescribing Committee shared care agreement for Growth Hormone information sheet.

Young people seen by members of the Nottingham Paediatric Growth Service will be retested at final height to see if they fulfill the adult growth hormone eligibility criteria as per NICE TA 64. Those fulfilling the criteria for continuation of growth hormone therapy will then be referred to the transitional clinic to discuss further management by the adult endocrinology service. There is no shared care agreement for adult growth hormone patients and thus the specialist will keep the GP informed regarding this transitional process.

Primary Care Prescribers' Roles and Responsibilities

The Primary Care Prescriber will be responsible for:

1. Ensuring that they have the information and knowledge to understand the therapeutic issues relating to the patient's clinical condition.
2. Undergoing any additional training necessary in order to carry out a practice-based service.
3. Agreeing that in his / her opinion the patient should receive shared care for the diagnosed condition unless good reasons exist for the management to remain within secondary

care. If shared care is not agreed, then they will inform the Specialist of their decision in writing within 14 days.
4. Prescribing the maintenance therapy in accordance with the written instructions contained within the information sheets, and communicating any changes of dosage to the patient.
5. Reporting any adverse effect in the treatment of the patient to the consultant.
6. The Primary Care Prescriber will take the advice of the referring consultant if there are any amendments to the suggested monitoring schedule.
7. The Primary Care Prescriber will ensure that the patient is given the appropriate appointments for follow up and monitoring, and that defaulters from follow up are contacted to arrange alternative appointments. It is the Primary Care Prescriber's responsibility to decide whether to continue treatment in a patient who does not attend appointments required for follow up and monitoring.

Community Pharmacist's Roles and Responsibilities

1. The community pharmacist will professionally screen prescriptions to ensure they are safe for the patient and contact the prescriber if necessary to clarify their intentions.
2. The community pharmacist will ensure prescriptions for GH are prescribed by brand and contact the prescriber if necessary to clarify their intentions.
3. The community pharmacist will fulfill legal prescriptions for medication for the patient unless they are considered unsafe.
4. The community pharmacist will counsel the patient on the proper use of their medication.
5. The community pharmacist will advise patients suspected of experiencing an adverse reaction to their medicines to contact their GP and complete a yellow card report as appropriate.

Patient's / Carer's Roles and Responsibilities

1. The patient / carer will take / administer their medication as agreed, unless otherwise instructed by an appropriate healthcare professional.
2. The patient (and carer if required) will attend all follow-up appointments with GP and specialist. If they are unable to attend any appointments, they should inform the relevant practitioner as soon as possible and arrange an alternative appointment.
3. The patient / carer will inform all healthcare professionals of the patient's current medication prior to receiving any new prescribed or over-the-counter medication.
4. The patient / carer will report all suspected adverse reactions to medicines to their GP.
5. The patient / carer will store their medication securely away from children as necessary.
6. The patient / carer will read the information supplied by their GP, specialist and pharmacist and contact the relevant practitioner if they do not understand any of the information given.

An easy read patient information leaflet is available from the European Society for Paediatric Endocrinology.

REFERENCES

NICE TA 188: Human growth hormone (somatropin) for the treatment of growth failure in children (review) July 2010. Available at www.nice.org.uk
NICE TA 64: Human growth hormone (somatropin) in adults with growth hormone deficiency August 2003. available at www.nice.org.uk

ORIGINAL AUTHORS

Dr Tabitha Randell, Consultant Paediatric Endocrinologist	Nottingham University Hospitals

James Sutton, Specialist Interface and Formulary Pharmacist	Nottinghamshire Area Prescribing Committee

USEFUL CONTACTS

QUEEN'S MEDICAL CENTRE SWITCHBOARD: 0115 9249924

Consultant or department	Daytime contact	Out of hours contact
Consultant Paediatric Endocrinologists		On-call paediatric endocrinologist via switchboard
Dr Tabitha Randell	Extension 82336	
Dr Louise Denvir	Extension 82336	
Dr Pooja Sachdev	Extension 82367	
Specialist Endocrine Nurses		
Jo Benson	Extension 85123	
Beki Glen	Extension 85123	

During normal working hours, parents and families should contact the paediatric endocrine nurses as detailed above. In the evening and at weekends/bank holidays, they should contact QMC on 0115 924 9924 and ask to speak to the paediatric medical registrar on-call. Alternatively, patients' families should contact their relevant home care company.
Care provided through other Trusts will be in close liaison with locally based Consultant Paediatricians.

Fast Track Referral
Contact Dr Louise Denvir, Dr Pooja Sachdev or Dr Tabitha Randell either through their secretaries (0115 9249924 ext 82336 or 82367) or page through switch. Alternatively, contact QMC switchboard and ask to speak to the paediatric endocrinologist on-call.

Other Supporting Information

Child Growth Foundation
www.childgrowthfoundation.org
Turner Syndrome Support Group
www.tss.org.uk

The Pituitary Foundation
www.pituitary.org.uk

British Society of Paediatric Endocrinology and Diabetes
www.bsped.org.uk