

This information sheet is for parents and carers of children who have an additional support need due to chronic illness or disability.

What is the National Support Needs System?

This is a health information system which holds the records of children who have been identified as having an additional support need associated with a chronic disability or health condition. The records include any information about specific health problems that your child may have and what kind of support they may need.

It enables early identification, assessment and co-ordination of care from birth to school leaving age.

Consent

This is a voluntary system and is entirely up to you whether you wish your child to be referred.

We will require your written consent to allow us to hold your child's details on the system and to share any reports with the relevant professionals involved with your child's care.

What does "support needs" mean?

The National Support Needs System (SNS) explains the term in the following way:

"Children may be deemed to have a support need if they require additional facilities such as a therapy, piece of equipment or other resource, over and above those usually given to all children. This additional requirement should be present for 6 months or more."

What are the benefits of going onto the Support Needs System?

Initially, a Community Paediatrician will become involved and will be responsible for overseeing the medical and support care of your child in the community. He or she will establish and maintain links with other professionals already known to the family e.g. Allied Health Professionals, GP, Health Visitor, School Nurse.

Being on the Support Needs System helps in sharing up-to-date information for parents/carers and professionals.

It will minimise the number of times similar information is requested by professionals from parents/carers.

It also helps us identify children with additional health screening requirements associated with their condition. It enables us to refer your child for additional dental review if appropriate (see Dental Section).

If you move within Lothian the co-ordination of your child's care is transferred to a corresponding Community Paediatric Team.

What will happen once my child is on the Support Needs System?

Reports produced by the Community Paediatrician will be shared with yourselves and involved professionals with your consent.

Future assessments will be planned in partnership with you. We aim to offer regular assessments in the early stages when your child's support needs are evolving and at key transition (nursery / primary / secondary / school leaving) stages. When regular review with the Community Paediatrician is no longer required your child can remain on SNS with a 'No Planned Assessment' status. This still

means that you or any involved professional can always directly request a service or review by the Community Paediatric Service.

Why does the Support Needs System include a dental link?

Often children with support needs will also have additional dental needs because:

- they may have more dental disease which can compromise their general health
- they may have conditions that make dental treatment more complicated
- they may find co-operation with dental treatment and mouth care more difficult

Many children manage well attending the local dentist with the rest of their family, however we are aware that for others this can be a struggle. If you find that your child struggles to cope with your usual dentist, or maybe even taking them to a dentist is difficult the SNS can link your child to the Public Dental Service to offer some additional input in one of our clinics where staff are experienced in working with children with additional support needs.

The Dental Service will contact you by letter to offer you appropriate options.

Confidentiality of data

The Support Needs System is part of the Scottish National Child Health Systems and as such is registered under the Data Protection Act.

Anonymised patient data may be used for purposes of audit and service planning.

Lothian Community Child Health departments

If you need to contact your Community Paediatrician, please contact the appropriate department below:

Edinburgh:	Royal Hospital for Children and Young People, 50 Little France Crescent, Edinburgh, EH16 4J 0131 312 0511
East & Midlothian:	Musselburgh Primary Care Centre, Inveresk Road, Musselburgh, EH21 7BP 0131 446 4123
West Lothian:	St John's Hospital, Howden Road West, Livingston, EH54 6PP 01506 524403