



Factsheet 24

The role of the GP

DR CAROLYN MOWAT, MA, MB.BCHIR, General Practitioner

BARBARA MOORE, RGN, RM, RHV, Children and Family Support Worker, Children's Specialist Services, Sense

Children with CHARGE may well spend a lot of time in hospital and will probably be involved with a large group of professionals and specialists.

As the family GP, you may be one of the few professionals who has known the family during the antenatal period and before diagnosis – and can look at the family as a whole and be aware of their previous medical history.

Each child with CHARGE is an individual and faces their own difficulties. In the rare event that you come across other children with the same diagnosis, it is important not to compare.

Things to think about

- **How much support does the family have?**

Is there extended family nearby who are willing to help? Do the parents have to rely entirely on themselves and each other? Do they have a support network of friends and will they be able to maintain their friendships with all the hospital visits and admissions etc?

- **Siblings:** Brothers and sisters may find the situation stressful and this can be manifested in health and well being (e.g. developing eczema, anxiety, sleep difficulties etc.).

- **Mental Health:** Parents will be under a huge amount of stress, not only due to the complex needs of their child, but also because children with CHARGE are often very poor sleepers. Some babies and children may not like to be touched for a variety of reasons and it may be difficult for parents to bond with their child.



Postnatal depression is a very real possibility under such circumstances, and parents may benefit from talking therapies and/or medication. Additional short breaks (respite) support may also be helpful. You may be the only professional with knowledge of previous mental health issues within the family that need to be taken into consideration.

- **Weight and development** will be atypical and is usually monitored by the specialists involved. Routine developmental assessments are not really appropriate for these children and will only serve to highlight the differences between themselves and their peers.
- **Infection control:** Children with CHARGE are very vulnerable to infection. As a consequence of their



increased vulnerability, it is important to consider either undertaking a home visit, or providing the last surgery appointment, to reduce the child's contact with other unwell people. The provision of a separate waiting area/room for consultation may be helpful.

Think carefully about hand washing and the cleaning of equipment.

- The **immunisation** programme can be disrupted and it will be necessary to ensure that this is completed.
- It can be helpful to identify a person within the practice to be the main point of contact for the family

Do

- Consider setting up a 'major alert' box on the child's file to contain:
 - CHARGE syndrome
 - Hospital consultant (and contact details)
 - Primary carer (and contact details).
- Be aware of all the anomalies associated with this syndrome, including later onset features. See 'CHARGE syndrome: major and minor medical diagnostic criteria plus later onset features' article in Sense's CHARGE pack for practitioners.
- Provide input to the Team Around the Child Meetings /Professional Meetings /Child in Need meetings – especially as you may have known the family before their child was diagnosed and can help to advocate for them.
- Refer the family to a local children's hospice as they may be able to provide additional short breaks support.
- Ensure that the family are aware of the CHARGE Family Support Group (www.chargesyndrome.org.uk) and the work of Sense Children's Specialist Services (www.sense.org.uk) and how they can be accessed.
- Be aware the family may need to have medical/nursing support at home.
- Please print off the template and add to the child's file.

Don't

- Be afraid to contact Sense Children's Specialist Services (www.sense.org.uk) for help and advice for yourself if you would like support.
- Compare children with CHARGE – they are all different.

Created: November 2013
Review due: November 2015
www.sense.org.uk





A proposed template for a child with CHARGE syndrome:

Child's name:	DOB:	Tick
Hospital consultants (names and contact details):		
Most recent date of hospitalisation:		
Date of discharge:		
Discharge letter in notes		
Follow-up plan in notes		
Name of primary GP contact with the family on any discharge from hospital and follow up if needed.		
Be aware the family may need to have medical/nursing support at home with surgical supplies.		
Be aware of all the anomalies associated with this syndrome – including later onset features and look out for them. See 'CHARGE syndrome: major and minor medical diagnostic criteria, plus later onset features' article in Sense's CHARGE pack for practitioners.		
Regular review of medication.		
Immunisation programme completed.		
Refer the family to a local children's hospice for additional short breaks support.		
Provide details of the CHARGE Family Support Group (www.chargesyndrome.org.uk) and the work of Sense Children's Specialist Services (www.sense.org.uk).		
Contact Sense Children's Specialist Services (www.sense.org.uk) for help and advice for yourself if you would like support.		