



## Factsheet 23

### Guidance for Health Visitors

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Children with CHARGE syndrome may well be in hospital for a long time or have frequent hospitalisations. They will probably be involved with a large group of professionals and specialists.

As the family health visitor, you may be the only professional to have known the family prior to diagnosis and/or the only person looking at the family as a whole.

Each child with CHARGE is an individual and faces his or her own difficulties so – in the rare event that you have 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 friendships with all the hospital visits and admissions etc?
- Brothers and sisters may well be overwhelmed by what is happening and worried about the future. Do they need help with siblings groups, young carers groups or counselling in order to help with this?
- Weight and development will be atypical and is usually monitored by the specialists involved. Routine developmental assessments are not really appropriate to these children and will only serve to highlight the differences between themselves and their peers.
- Children with CHARGE are very vulnerable to infection. Think carefully about hand washing and the cleaning of equipment and toys. Should you need to weigh a child always ensure the scales are scrupulously clean.
- Families of children with CHARGE may be unable to attend local support groups unless they are small, quiet and have a visually uncluttered environment. Once again, the need for infection control is paramount and an understanding of the risk of infection to a child with CHARGE is essential. Special Needs playgroups may be suitable but as children with CHARGE will probably have poor eyesight, hearing and balance/mobility difficulties they are vulnerable to others.
- 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.

- If there is a local children's hospice nearby, the family may be able to access not only excellent family therapists but also peer group support for themselves and their children.
- There could be financial difficulties caused by extra transport and living costs and the possibility of time off work and therefore reduced income.

## Do

- Contact the family and ask if they would like you to be involved. For example, would they like a hospital visit? Would they prefer regular phone calls?
- Liaise with the hospital staff about the child's condition, how things are likely to proceed and when they expect a discharge. Contact the family on discharge and arrange a visit.
- Even though it may not be appropriate to do developmental checks and 'weigh ins', these are good points of contact dates to phone or visit the family – especially if their extended support network is limited.
- Attend Team Around the Child meetings/professional meetings/Child in Need meetings if possible. This is important as you may have known the family before their child was diagnosed and can help to advocate for them. Attending meetings will also give you a good insight into just how complicated and difficult life is for this family.
- Ensure that the family are aware of the CHARGE Family Support Group ([www.chargesyndrome.org.uk](http://www.chargesyndrome.org.uk)) and the work of Sense Children's Specialist Services and how they can be accessed.
- Are you aware of any welfare benefits this family may be entitled to? If this is difficult to discuss, give the Department of Work and Pension's Benefits helpline number or advise that they contact Citizens Advice.
- A referral to the local sensory support services and/or Portage may be appropriate. Please request input from someone who has a qualification in multi-sensory impairment and experience of working with children who have CHARGE.

- The family may need to have medical/nursing support at home and also some kind of respite provision in the future, so may need a referral to social services in order to plan for this. It could take the form of specialist workers trained in multi-sensory impairment working with the child at home or in nursery/playgroup settings. It could also be a Link Family or respite provision in a setting elsewhere. At some point in the future, the child may well need specialist equipment or home adaptations.
- Contact Sense Children's Specialist Services ([info@sense.org.uk](mailto:info@sense.org.uk) or 0845 127 0066) for help and advice for yourself if you would like support.

## Don't

- Be offended if you are asked not to visit – as families often feel overwhelmed by the number of professionals they see.
- Be afraid to act as an advocate if the family need your support.
- Compare children with CHARGE.

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