



## Factsheet 28

# CHARGE syndrome in adulthood

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Much of the research carried out about CHARGE in the 1980s and 1990s focussed on the younger age-group that "typically had severe characteristics" (Hartshorne, 2006, p. 9). This may be due to lack of identification of the condition in adults as the condition has only been recognised since 1979. Also (as suggested by Hartshorne, 2006) because individuals with serious, less treatable characteristics were less likely to survive.

With the first large group of children diagnosed with CHARGE now reaching adolescence and adulthood, more information is becoming available about people in these age-groups – including the identification of longer-term manifestations of the condition that are beginning to emerge.

### Later onset features

According to Searle *et al.* (2005) there is evidence that "As individuals with CHARGE syndrome age, they face an evolving set of medical issues" (p. 347).

These include scoliosis and pubertal delay which are already generally recognised, but can also include:

- migraines
- epilepsy
- endocrine deficiencies leading to difficulties with osteoporosis and obesity
- sleep apnea
- cataracts
- retinal detachments
- progressive hearing loss
- renal failure

(See Searle *et al.*, 2005; Issekutz *et al.*, 2005; Hartshorne, 2006).

It is important to stress that not all these conditions will be found in each individual with CHARGE.



However, professionals working with adults with CHARGE need to be aware of the possibility and ensure that the development of any of these conditions is swiftly diagnosed and an appropriate response made.

### Support during adulthood

The heterogeneous nature of CHARGE syndrome and the CHARGE population is often mentioned in literature (e.g. Hartshorne *et al.* 2011) and this implies that adults with this condition are likely to have varying degrees of support needs.

At one end of the spectrum some adults with CHARGE are able to live completely independently; others will require high levels of support.

The needs of each individual with CHARGE will be unique and the use of a Person-Centred Planning (PCP) approach can ensure that each person is effectively

supported to achieve a rich and fulfilling life (see Department of Health, 2010). PCP is a process of planning for an individual and shaping a service around their individual strengths and needs – rather than fitting the person into an existing package or model of support.

The list below sets out the areas that should be considered by professionals supporting an adult with CHARGE syndrome – particularly those that have a higher level of support needs.

### What the individual with CHARGE may need support to develop (adapted and developed from Majors, 2011):

- How to communicate effectively
- How to make choices
- How to be social and be part of a group
- How to negotiate
- How to help out
- How to take turns
- Functional life skills
- How to be organised and plan for each day
- How to cope with difficult/more challenging situations
- How to manage their behaviour
- A sense of self and their self-identity (this includes understanding their own condition)
- An understanding of their strengths and limitations.

### What professionals supporting the individual with CHARGE may need to develop/ provide:

- An awareness and understanding of the unique characteristics of the individual with CHARGE and the implications of these
- Use of a Person-Centred Planning approach
- An ability to communicate effectively
- Negotiation and empowerment
- Opportunities for choice-making, identifying what is motivating (what I like/dislike), meaningful and important
- An ability to follow the individual's lead
- Recognition of people preferences and how to respond to these
- Modelling of social interactions and how to respond in different situations
- Provision of a visual calendar/timetable
- Assistance to work in an organised manner, to follow a sequence through and with re-direction back to a task when needed
- Support to develop functional life-skills
- A flexible approach that allows for frequent sensory breaks and the provision of less demanding activities when needed
- Consistency of approach
- Learning to read 'behaviour signals' and how to respond to support positive behaviour

- Strategies that can be used to manage more difficult/challenging situations and helping the individual with CHARGE learn how to draw on these when needed
- A social/emotional development programme to encourage self-esteem and positive self-identity
- With consent, and where appropriate, to provide information about their condition and what this means for everyday living
- Identifying strengths and building upon these
- Identifying desires/ dreams and realistically helping to achieve them.

Created: November 2013  
 Review due: November 2015  
[www.sense.org.uk](http://www.sense.org.uk)



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