

Life expectancy of children with cerebral palsy

J L Hutton, K Hemming and UKCP collaboration

What is UKCP?

Information about the physical effects of cerebral palsy on the everyday lives of children and their families has been difficult to establish in the past. There are five long-term studies of people with cerebral palsy which collect information about children within specific local areas. They are the Mersey Region Register, North of England Collaborative Cerebral Palsy Survey, 4child (which was the Oxford Register of Early Childhood Impairment), the Cerebral Palsy Register for Scotland and the Northern Ireland Cerebral Palsy Register. These registers have collected data on people born during 1966-1996 (Mersey), 1960-1997 (North of England), 1981-1996 (Northern Ireland), 1984-1997 (4child) and 1984-1997 (Scotland). The funds to run these registers have varied, so the later years of Mersey and Scotland are not yet complete.

In order to co-ordinate good information, and to help find funding for continuing work, the *UK Collaborative Network of Cerebral Palsy Registers* was set up. The UK Collaborative Network of Cerebral Palsy Registers brings together the five active cerebral palsy registers described above. We aim to help studies of how common cerebral palsy is, why it occurs, and how long children affected with CP are likely to live. We also consider the services which need to be provided for children with cerebral palsy and their families.

The data base which has been created provides the best available information on cerebral palsy in the UK. There are now data on 6900 children in the UKCP data base. This includes some information about children who acquired cerebral palsy after they were one month old. The summaries below are based on children who acquired cerebral palsy before they were a month old. No-one can be identified from the information held by UKCP.

Jane Hutton, a professor of medical statistics at the University of Warwick, has had funds from the Medical Research Council to create the UKCP data base. Her research with Karla Hemming, another statistician, has focused on the survival of people with cerebral palsy. They have studied the effect of the type of cerebral palsy, and the ability to walk, feed or dress and communicate on survival. They have considered whether the survival of people with cerebral palsy varies between regions in the UK, and changes for those born more recently. They also consider what causes the deaths of those who die young.

This leaflet only focuses on one limited area of peoples' lives. The University of Newcastle researchers have studied over many years how cerebral palsy affects peoples' lives. Allan Colver, a community paediatrician at the University of Newcastle, has a European Union grant to assess the quality of life of people with cerebral palsy, in UK and several other European countries. Helen Dolk, an epidemiologist at Queens University, is studying how cerebral palsy varies with socio-economic conditions.

How are children with CP affected by their condition?

The UKCP registers collect information on how well the children can walk, or if they use a wheelchair, and whether they can dress and feed themselves. Children's hearing and sight are considered, and whether they have learning difficulties. The type of CP is also recorded. These are aspects of CP which are important to quality and length of life.

- There are more boys born with cerebral palsy than girls.
- For every 100 girls with cerebral palsy, there are 135 boys with cerebral palsy.
- Just under a half of children with cerebral palsy were born prematurely.
(Babies born before 37 weeks gestation are defined as premature.)
- Just over a half of children with cerebral palsy are affected by bilateral spastic cerebral palsy.
- A third of children with cerebral palsy are affected by hemiplegic spastic cerebral palsy.
- About one in twenty children with cerebral palsy have dyskinetic and ataxic cerebral palsy.
- About one in three children with cerebral palsy are unable to walk.
- About one in four children with cerebral palsy cannot feed or dress themselves.
- About one in five children with cerebral palsy cannot walk, and cannot use their hands.
- About three in ten children with cerebral palsy have severe learning difficulties
- About one in fifty children with cerebral palsy are deaf.
(Deaf means severe hearing loss in both ears.)
- About one in eleven children with cerebral palsy are blind.
(Blind means worst than 6/60 in the better eye, or no useful vision.)
- About one in four children with cerebral palsy are reported to have epileptic seizures.

How long do children with cerebral palsy live?

The longer you live, the longer you are likely to live! Once a child has lived to age ten years, we know they have a better chance of living a long life. As you might expect, the more severe impairments a child has, the less likely it is that he or she will live to be an adult. The examples below are mostly for two year old children.

- A child who is mildly affected by CP can expect to have much the same length of life as a child without CP.
- A child of two who cannot walk has three chances in four to live to adulthood.
- Of a hundred children aged five who cannot walk, and cannot feed or dress themselves, 63 will live to 20, and 50 will live to age 30.
- A child of two who cannot walk, and cannot feed or dress himself, and has severe learning difficulties is as likely as not to live to age 25.
- Half of five year old children who cannot walk, and cannot feed or dress, have severe learning difficulties and are blind will live to be adults.
- A quarter of two year old children who cannot walk, and cannot feed or dress, have severe learning difficulties and are blind will live into their thirties.
- A child of two who cannot walk, but is not otherwise severely affected, is very likely (95%) to live to 20 years.
- A child of two who cannot walk, or feed and dress herself, but who can see, and does not have severe learning difficulties has a four in five chance of reaching age 20 years.
- A child of two who cannot walk, or feed and dress herself, and has severe learning difficulties, but who can see, has a three in five chance of reaching age 20 years.
- A child of two who cannot walk, or feed and dress herself, and has severe learning difficulties, and is blind has a two in five chance of reaching age 20 years.
- Children who were born preterm have a slightly better outlook than a child with the same impairments who was born at term.
- If a person with cerebral palsy lives to age 18, they are more than likely to live beyond age 40.
- A third of those children with cerebral palsy who die young have cerebral palsy as their underlying cause of death.
- One in five of those children with cerebral palsy who die young have respiratory disease.
- Only one in 25 of those children with cerebral palsy who die young have epilepsy as their underlying cause of death.
- Adults with cerebral palsy die from the same diseases as other people. Heart attacks and strokes are common, as are cancers.

Further information

If you wish to read the academic articles written by members of UKCP, you can check the list at UKCP web site: <http://www.liv.ac.uk/PublicHealth/ukcp/UKCP.html>. The main articles from UKCP registers are listed below. A librarian could help you find these, or you can contact SCOPE:

Gary Birkenhead
About Cerebral Palsy Manager
Scope
gary.birkenhead@scope.org.uk

More general information and support can be obtained through the Scope Cerebral Palsy Helpline on 0808 800 3333.

Thank you

We would like to thank the MRC for providing the funding to support this research. We would also like to thank SCOPE, ONS, and UKCP colleagues for their support.

Jane Hutton, and Karla Hemming
The University of Warwick, Coventry, CV4 7AL
13 June 2006

References

- [1] P O D Pharoah, T Cooke, L Rosenbloom, and R W I Cooke. Trends in the birth prevalence of cerebral palsy. *Arch. Dis. Ch.*, 62:379–284, 1987.
- [2] S N Jarvis, J S Holloway, and E N Hey. Increase in cerebral palsy in normal birthweight babies. *Archives of Disease in Childhood*, 60:1113–1121, 1985.
- [3] J Parkes, H Dolk, N Hill, and S Pattenden. Cerebral palsy in Northern Ireland. *Paed. Perin. Epid.*, 15:278–286, 2001.
- [4] A Johnson and R King. A regional register of early childhood impairments: a discussion paper. *J Public Health Med*, 11:352–363, 1989.
- [5] LW Mutch, E Alberman, B Hagberg, K Kodama, and MV Perat. Cerebral palsy epidemiology: Where are we now and where are we going? *Dev. Med. & Child. Neur.*, 34:547–555, 1992.
- [6] P M Evans, S J W Evans, and E Alberman. Cerebral palsy: why we must plan for survival. *Arch. Dis. Ch.*, 65:1329–1333, 1990.
- [7] D Strauss, R M Shavelle, and T W Anderson. Life expectancy of children with cerebral palsy. *Ped. Neurol.*, 18:143–149, 1998.
- [8] J L Hutton, A F Colver, and P C Mackie. Effect of severity of disability on survival in north east England cerebral palsy cohort. *Arch. Dis. Ch.*, 83:468–474, 2000.

- [9] J L Hutton and P O D Pharoah. Effects of cognitive, sensory and motor impairment on the survival of people with cerebral palsy. *Arch. Dis. Ch.*, 86:84–89, 2002. Commentary L Rosenbloom 89-90.
- [10] D Strauss, W Cable, and R Shavelle. Causes of excess mortality in cerebral palsy. *Dev. Med. & Child. Neur.*, 41:580–585, 1991.