An introduction to ageing and cerebral palsy

The concept of ageing and cerebral palsy is now becoming more recognised and more research is being undertaken. However many people, including some professionals, think that because cerebral palsy is a ‘non-progressive disorder’ physical functioning will remain much the same throughout life. This isn’t necessarily the case. Whilst some people lose no more function than might be expected from the usual ageing process, some people find their function deteriorating more quickly and new physical problems can emerge. This factsheet explains why this might occur and what might be done to limit potential deterioration.

It is a common perception that growing older brings with it poor physical health, mental incapacity and an inability to function independently. Whilst physical abilities do decline with age, it is slower and to a lesser degree than you may think. The impression that older people experience severe physical decline is partly because of confusion between primary ageing (changes brought about by increasing age) and secondary ageing (changes from disease, disuse or abuse of our bodies). In fact, many people retain good physical health into their seventies and beyond.

However, for those who have lived a lifetime with a physical impairment, ageing effects can become apparent earlier than expected. Cerebral palsy is an example of a developmental disorder in which physical functioning can deteriorate with ageing as a result of poor mechanical efficiency.

Problems people report as they get older
There is little published scientific evidence on the physical effects of ageing and cerebral palsy; however surveys have highlighted some of the problems that people encounter. What is clear is that people with cerebral palsy age in the same way as non-disabled people
(primary ageing) but some people with cerebral palsy may experience secondary ageing effects. These are likely to be the long-term effects of the original impairment.

Below are some of the more common problems reported by people in their thirties and forties or, sometimes, a little earlier:

- Increased levels of pain and discomfort
- Osteoarthritis (pain and stiffness in the joints)
- Increase in spasms
- Increase in contractures (shortening of muscles)
- Less efficient motor control
- Joint problems
- Tight muscles
- Gastro-intestinal (digestive system) problems
- New back pain
- Increase in back pain
- Emergence of incontinence
- Increase in incontinence
- Loss of joint flexibility
- Reduced energy levels and fatigue

Some risk factors associated with loss of function
In many cases the reasons for the emergence of new problems or aggravation of an existing condition is not too difficult to understand. Below are some factors which may contribute to secondary ageing effects:

- Poor wheelchair seating and posture
- Spinal deformities
- Contractures (where joints are held in one position due to muscle shortening)
- Absence of appropriate movement of limbs and joints
- Persistence with walking when it is becoming increasingly difficult
- Exhaustion
- Ending of long-term physical therapy
- Weight gain
• Severe learning disability
• Ignoring the body’s warning signals such as pain, discomfort and stiffness
• Physical injury
• Inappropriate orthopaedic surgery
• Absence of appropriate rehabilitation following surgery

Poor wheelchair seating and posture may mean that there is inadequate support which can make existing spinal problems worse, causing pain and discomfort and sometimes loss of function in the limbs. Through lack of appropriate exercise tight muscles may develop into contractures causing deformities in limbs.

Persistence in walking when the legs are adversely affected may cause long-term problems elsewhere, such as arthritis in the joints and pain and discomfort in the back, as other muscles try to compensate for the awkward movement. Physical exhaustion may follow from taking too little rest resulting in an overall decline in physical and mental functioning.

Many people with cerebral palsy push themselves to their physical limit and thus have little in reserve. Consequently, recovery can take much longer following an injury or illness and, unless there is a rehabilitation programme following the injury or illness, recovery to previous levels of functioning may be slow.

Orthopaedic surgery can be helpful in the treatment of certain aspects of cerebral palsy, such as the prevention of spinal deformities and contractures. However, orthopaedic surgery on people with cerebral palsy requires particular expertise. Inappropriate procedures may be recommended by surgeons who do not have specialist knowledge of cerebral palsy, and lack of appropriate rehabilitation following surgery may contribute to delays in recovery, or even deterioration in physical functioning.

Ways of maintaining physical functioning
Whilst not everyone with cerebral palsy will lose a significant degree of physical functioning with ageing, some will lose function earlier than might be expected. Below are some ways of maintaining physical functioning.

• Ensure appropriate wheelchair seating and posture
• Spend time in various positions outside your wheelchair
• Adopt stretching exercises in order to stop muscles becoming tight
• Seek early and appropriate medical advice if new problems emerge
• Avoid excessive weight gain
• Avoid high levels of sustained pressure and stress
• Take regular and appropriate exercise, for example, swimming
- Consider occasionally using a powered wheelchair/motorised vehicle if walking is becoming difficult or physically demanding
- Seek regular reviews of physical functioning
- Seek advice on an exercise programme for joints and limbs from a physiotherapist with an interest/specialism in cerebral palsy
- Consider carefully the implications of any proposed surgery
- Seek a surgeon who has an acknowledged expertise/interest in cerebral palsy
- Ensure that a programme of rehabilitation/physiotherapy is in place following surgery

**NOTE:** Please seek medical advice before commencing a physical programme such as swimming or exercise routines.

- **When and how to seek help**

**Family Doctor (GP)**
A range of services are available for children with cerebral palsy and it is relatively straightforward to identify needs and to obtain professional help. Unfortunately, a comprehensive service for adults is not in place. It may therefore be beneficial to seek an annual check-up from your family doctor. In this way it may be possible to anticipate problems. Your family doctor may be able to refer you to therapy services, or to a medical consultant with an interest or expertise in cerebral palsy. However, your GP may have a limited knowledge of cerebral palsy - you may be the only patient on his/her register with this condition. If you can be informed about your own condition, it will help. If you are dissatisfied with the input from your doctor, you may ask for a second opinion.

**Alternative Therapies**
Many people find benefit from complementary therapies, including acupuncture, massage and aromatherapy. There are a number of books on the market that describe various alternative therapies. Unfortunately very few will relate specifically to disability or cerebral palsy but, as with such therapies, it is a case of discussing your needs with the therapist and finding out what helps you. It may be possible to access some of these therapies through your family doctor. For details of therapists in your area, get in touch with the Federation of Holistic Therapists:

18 Shakespeare Business Centre
Hathaway Close
Eastleigh
Hampshire
SO50 4SR
Tel: 023 8062 4350
Therapy services

If you would like to know more about therapy services such as physiotherapy, occupational therapy and speech and language therapy, a factsheet called ‘An Introduction to Therapy’ is available from Advice Service Capability Scotland or can be downloaded from Capability Scotland’s website. You can also speak to your GP. The following organisations can also be helpful:

The Chartered Society of Physiotherapy
14 Bedford Row
London
WC1 4ER
Tel: 020 7306 6666
Website: www.csp.org.uk

The College of Occupational Therapists
106-114 Borough High Street
Southwark
London
SE1 1LB
Tel: 020 7357 6480
Website: www.cot.co.uk

Royal College of Speech and Language Therapy
2 White Hart Yard
London
SE11NX
Tel: 020 7378 1200
Website: www.rcslt.org.uk

Capability Scotland Therapy Services
Capability Scotland offers a full range of Occupational Therapy, Physiotherapy and Speech and Language Therapy assessments. Treatment programmes can be arranged with training provided to support staff and parents. We also provide rebound and hydrotherapy assessments.
For further details and information about costs please contact:

Therapy Services Manager
Further reading

Cerebral palsy and ageing: A systematic review.
By Dr Diane Cox, Clare Veze and Chris Lewis
2005, 81 pages, ISBN 0946828334

A systematic review commissioned by Scope and carried out by St Martin's College, Lancaster. The aim of the review is to consider current knowledge on cerebral palsy, life expectancy, health and functional ability in adults with cerebral palsy and to start to explore some of the issues related to ageing effects.

£3.30 to individuals/£12.75 to organisations. Copies available from
Publications
PO Box 833
Milton Keynes
MK12 5NY
Tel: 01908 321049.

Download free Cerebral Palsy and ageing: Executive Summary pdf (200k)
Our Advice Service
Advice Service Capability Scotland is a national disability advice and information service. We specialise in information on cerebral palsy.

We offer:
• information on Capability Scotland services
• advice on cerebral palsy
• general advice on disability issues

We also have a small lending library with resources about cerebral palsy and children's books about disability.

You can get in touch with us by calling, e-mailing, dropping in or writing a letter.

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This factsheet can be made available in other formats e.g. tape, large print.

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