



Finding out that you have HD can be extremely distressing for individuals and their family members, similarly living with HD over a period of time will cause distress at times while other times can feel completely manageable.

People's emotions and vulnerability change depending on how well they feel they are coping; some days coping can be easy whereas others can be very testing. Talking about worries and problems can be very beneficial but it is not always easy.

It is recognised that emotional distress can affect other areas of living, for example;

- Reduced motivation
- Lethargy and feeling tired
- Becoming withdrawn
- Unable to carry out daily tasks
- Loneliness and social isolation
- Feeling low in mood
- Access to appropriate support can help to reduce loneliness and social isolation as well as improve general health and well being. The types of supports available include
- 1-1 support i.e. specialist advice, counselling, befriending or mentoring;
- Group services i.e. day centers, lunch clubs & social group schemes; or,
- Wider community engagement programmes i.e. outreach programmes or volunteer schemes.

It is important to keep in mind that activities to reduce social isolation should be appropriate for the individual person and not just based on more contact with people; it is possible to feel lonely even when surrounded by others.

Possible signs and symptoms that develop when someone is isolated are

- Physical – general ill-health, increased risk of drug/alcohol use
- Emotional – reduced confidence, lower self-esteem, anxiety or depression.
- Cognitive – shortened attention span or increased forgetfulness

Caring for someone with HD can be a life changing experience. People with HD eventually need

daily or round the clock care which can make you feel alone. The kind of daily challenges you face can be tough on your physical and mental health. Often the hardest thing is seeing the loss or change in former personality; learning how to manage your own stress through relaxation techniques, meditation or deep breathing can help reduce stress and boost mood and energy levels. One of the most important things as a carer is to take care of yourself.

- Seek help; reach out to family, friends or volunteer services
- Stay socially active; try to stay connected to friends and family and accept the support they give.
- Talk to others in similar situations; joining a support group can provide opportunity to speak openly about the experience with other carers.

Useful Links

Glasgow City Carers Partnership

Provides a universal offer of information & advice to all carers in the city through:
Carer Information & Support Unit

0141 353 6504

www.glasgow.gov.uk/carers

Samaritans

Email: jo@samaritans.org

www.samaritans.org

08457 909090

Breathing Space

A confidential phone line for anyone in Scotland feeling low, anxious or depressed.

www.breathingspacescotland.co.uk

0800 838587

Carr Gomm

Supporting people and communities

www.carrgomm.org

0300 6663030

Centre for Independent Living

www.gcil.org.uk

0141 550 44 55

Capability Scotland

www.capability-scotland.org.uk

0131 337 9876

My Bus

www.spt.co.uk

0845 1284025

Outside the Box
www.otbds.org
0141 419 0451