

NHS Fife Department of Psychology

Living with a condition from birth

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Many medical conditions can be present from birth, or early childhood. These may require lifelong medical intervention. Understandably, this can bring challenges for the individual, as well as parents and caregivers.

Living with a medical condition from an early age can impact upon a person's development in many areas – emotionally, physically and socially. It may not be possible for a child to engage in activities that other children can and their condition may cause them to miss out on many things. This may lead to feelings of isolation, and the sense of being different from others. They may be singled out as being different amongst their peers and this can lead to bullying, or a sense of not 'fitting in'. Sometimes these feelings continue into adulthood and can affect a person's self-esteem. Also, if their medical condition requires long term interventions, they may miss periods of schooling which can impact on their education and social life.

In some cases, medical issues may appear 'invisible' to others and this can create some difficulties in terms of others not understanding how serious the condition is, or not believing that the individual has an illness at all. However, it has also been shown that those people who have lived with an illness since birth or early childhood show increased ability to cope with life challenges, have better understanding of others and a deep appreciation for the value of life.

Emotions

There may be a constant fear of repeated illness episodes, complications or even death. This can also contribute to feelings of worry and anxiety. Trips to hospital, medical procedures and contact with medical professionals can result in anxiety related to procedures and hospital admissions. It can be a scary and unfamiliar world for a child and these feelings can stay with us until adulthood. Parents can experience high levels of anxiety around the health of their child, worries about the future and how they and

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their child will cope with a lifelong illness. It can also be hard to cope with others being in 'control' of what happens – parents, doctors, surgeons. This can cause anxiety and worry and sometimes lead to low mood.

In some cases, medical procedures and admissions can be traumatic. Patients may find themselves having difficulty coping with feelings about such procedures and experience memories or even 'flashbacks' to particularly difficult events. These memories can feel very real and vivid, and might continue throughout a person's life, even if the original event was a long time ago. It may make them frightened to attend for treatment in the future and this will result in it being more difficult to manage their medical condition. If this has happened to you, your GP may be able to refer you to a Psychologist who can help you move on from these traumatic experiences.

Body Image

The impact of procedures on how someone's body looks and feels can also be a source of distress and worry. Living with a long term medical condition from birth may result in the need to learn to accept your body and feel comfortable in your own skin. This can be a lifelong process.

Seeking support

Feeling safe is very important when you live with a serious, lifelong medical condition. Social support from friends and family can help greatly in the management of a long term medical condition. If you are feeling lonely there are a wide range of support organisations for specific long term medical conditions who can offer advice and help. Please see the 'A-Z of Contacts for Physical Health Conditions' on <u>moodcafé</u>. Often people can feel depressed and worried because of their condition. It can also affect their self esteem and confidence. Further information on these issues can be found on <u>moodcafé</u>.

Visit moodcafe.co.uk for more helpful resources

