

# Talking About My Health Condition



**Top tips for  
and by young  
people living  
with long term  
conditions**

**Action for Sick Children (Scotland)** produced this with the help of young people living with long term conditions, who took part in our Stay Well Lanarkshire project. This aimed to help young people learn more about self managing their health condition by participating in workshops we developed and delivered; over 50 attended these. This booklet contains their top tips for other young people with long term conditions and on the flip side, top tips for parents, carers, health and education professionals on how to communicate better with one another.

## **Self Management definition**

Self management puts people living with long term conditions in 'the driving seat'. It supports and encourages people to access information and to develop skills that will enable them to live their lives on their terms.

**Self management is not a replacement for services**

**Self management does not mean having to manage alone without support**

**Self management is not an individual action, specific treatment or service**

(from Long Term Conditions Alliance Scotland, LTCAS [www.ltcas.org.uk](http://www.ltcas.org.uk))

**For Self Management to work, young people need**

- Appropriate and accessible information
- Belief in young people's ability to manage
- Time for young person to develop skills
- Effective communication with all involved
- Confidence to 'let go'

**When you go to your clinic or doctor,  
ask questions – making a list can help**

**Top Tip 1**

**Know your health condition inside out.  
Learn all you can from your doctor,  
nurse and parents/carers**

**Top Tip 2**





**Help is there all you have to do is ask**

**Top Tip 3**

**Set yourself goals you know you  
can achieve**

**Top Tip 4**

**Always be positive – don't hide your thoughts and don't be scared to talk with others about your health condition**

**Top Tip 5**

**Get in touch with other people – you're not the only one with a health condition**

**Top Tip 6**





# Useful Websites for Young People



[www.ascscotland.org.uk](http://www.ascscotland.org.uk)

Action for Sick Children (Scotland)

[www.nhsinform.co.uk](http://www.nhsinform.co.uk)

National Health Information Service provides advice and support for specific health conditions.

[www.nhs24.com](http://www.nhs24.com)

National Health Service (NHS) provides advice and support 'out of hours', public holidays and other times when your GP surgery is closed.

**[www.youngscot.org](http://www.youngscot.org)**

Young Scot provides information for young people including mental health, sexual health and physical health and well-being.

**[www.getthelowdown.co.uk](http://www.getthelowdown.co.uk)**

Young Scot information dedicated to 'getting the lowdown' on teenage health concerns.

**[www.ltcas.org.uk](http://www.ltcas.org.uk) and [www.myconditionmylife.org](http://www.myconditionmylife.org)**

Long Term Conditions Alliance Scotland campaigns and provides information on long term health conditions and self management.

**[www.hris.org.uk](http://www.hris.org.uk)**

Health Rights Information Scotland offers information and leaflets on consent, confidentiality, having your say, and your rights and responsibilities in the National Health Service (NHS).

**Young people want to be  
involved in their own healthcare  
(self management)**

**Top Tip 1**

**Talk with me, not at me about  
my condition**

**Top Tip 2**





iStockphoto

**Give me some control. Parents and doctors should listen to my opinions and suggestions**

**Top Tip 3**

**Don't talk in jargon and big words  
– I'm not stupid but don't assume I know it all either**

**Top Tip 4**

**Teachers shouldn't change the lesson plan without discussing it with me. I might not need or want special food or equipment. Respect my ability to adapt**

**Top Tip 5**

**Help me learn what I can do, not just the limitations because of my health condition (activity, food, treatment)**

**Top Tip 6**





“

‘Our role as **parents** is to make our young person as capable as they can be going through life. There needs to be engagement and discussion between the NHS and parents/carers regarding transition from paediatric to adult services.’ ***Parent of child with asthma***

‘We face a communication barrier in school when a young person can feel uncomfortable discussing their problem. Our challenges are to ensure learning isn’t interrupted and that all staff, including temporary staff, are well informed of the health issues and aware of emergency procedures.’ ***Secondary school guidance staff***

‘**Health care professionals** are challenged by the fact that young people do not always get the opportunity to express their views and it is often awkward to get the young person on their own to allow them to express their view. Sometimes, the parents speak for their children so allowing them to gain in confidence and be more independent is a barrier to overcome.’

”

**Action for Sick Children (Scotland)** is the only charity in Scotland dedicated to informing, promoting and campaigning on behalf of the needs of ALL sick children and young people within our healthcare system.

For more information in your language call **0131 553 6553**

For a full list of publications visit **[www.ascscotland.org.uk](http://www.ascscotland.org.uk)**

**Action for Sick Children (Scotland)**

22 Laurie Street, Edinburgh EH6 7AB

Telephone: 0131 553 6553

Website: [www.ascscotland.org.uk](http://www.ascscotland.org.uk)

E-mail: [enquiries@ascscotland.org.uk](mailto:enquiries@ascscotland.org.uk)

Action for Sick Children (Scotland) A company limited by guarantee, No 100114, and a Scottish charity, OSCR No SC006016, Registered Office 22 Laurie Street, Edinburgh EH6 7AB

# Talking About My Health Condition



Top tips  
from young  
people with long  
term conditions for  
those working  
with them

