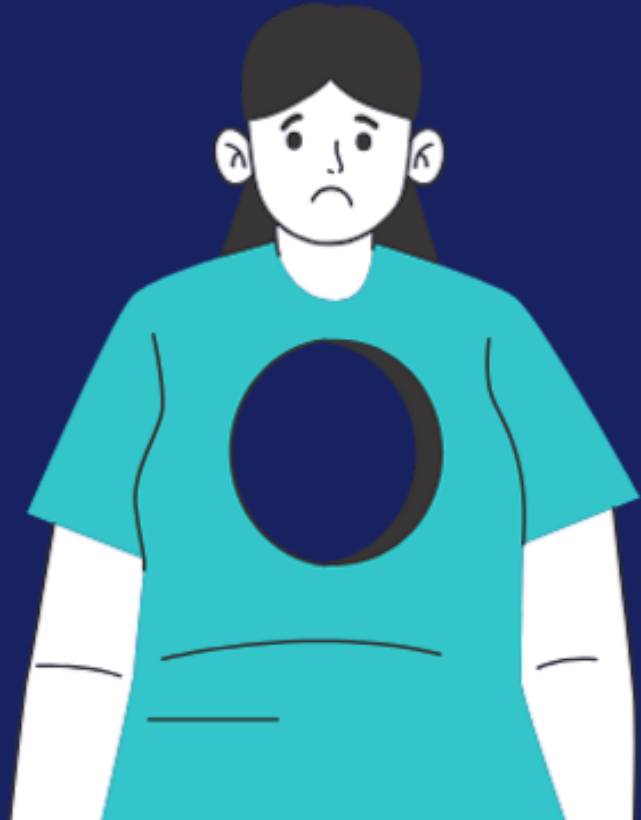


**Don't
assume
I'm ok**



**I have a lot to
cope with**

**#BrainAwarenessWeek
#DontAssumeImOk**



Don't assume I'm ok

*Some days he can
manage in school no
problem, on others
he just can't cope*

I have a lot to cope with

#BrainAwarenessWeek
#DontAssumeImOk






Overnight, Bruce developed severe contamination fears and obsessive rituals.

He refused to touch everyday objects, demanded multiple baths and showers, and followed rigid bathing routines. He had tics, his legs were stiff and he walked with a limp, and his hand and wrists locked into uncomfortable positions. He also suffered with separation anxiety.

Don't assume I'm ok I have a lot to cope with

**#BrainAwarenessWeek
#DontAssumeImOk**





Bruce's symptoms continue to **fluctuate**, most notably when he is fighting an infection, and he continues to find dealing with his symptoms incredibly challenging.

Some days he can manage in school no problem, on **others he just can't cope** with the environment and becomes completely overwhelmed.

Don't assume I'm ok I have a lot to cope with

#BrainAwarenessWeek
#DontAssumeImOk



**Don't
assume
I'm ok**



**Change can be a
kind of grief**

**#BrainAwarenessWeek
#DontAssumeImOk**



Don't assume I'm ok

*We don't talk
about loss,
death, or grief
enough*

Change can be a kind of grief

**#BrainAwarenessWeek
#DontAssumeImOk**






Loss is a strange thing. We don't talk about loss, death, or grief enough. We know it exists, and we support those going through it, but loss is more than death.

'Loss' encompasses many things, from a physical sudden loss, to a slow and ongoing loss.
For me, I experienced both through my Mum's MS.

Don't assume I'm ok change can be a kind of grief

**#BrainAwarenessWeek
#DontAssumeImOk**





Slowly and all too quickly, I had lost pieces of my mum over the course of 8 years.

The loss of my mum was neither quick, nor was it simple. It is therefore important to talk about loss, not only to support those going through it, but to acknowledge the varying types of loss that people go through.

Don't assume I'm ok change can be a kind of grief

#BrainAwarenessWeek
#DontAssumeImOk



**Don't
assume
I'm ok**



**I carry more responsibility
than you know**

**#BrainAwarenessWeek
#DontAssumeImOk**



Don't assume I'm ok

*I felt very
strongly about
looking out for
my Mum*

I carry more responsibility than you know

#BrainAwarenessWeek
#DontAssumeImOk





Looking back now, knowing what a young carer is, of course I was. But to me, when I was a child looking out for my Mum, I wasn't. **To me, I was just looking after my Mum** and that was fine.

I think, looking back, the label wasn't important. **What was important was support.** I knew so much about my Mum, and was also one of the people looking out for her, but in my own way.

Don't assume I'm ok I carry more responsibility than you know

#BrainAwarenessWeek
#DontAssumeImOk



My advice to family and professionals then, is:

Think about the 'mini-experts' in someone's life. Check in with them, ask them what they think – **include them.** Children pick up on so much without you knowing, make sure they know they are valued, beyond just labelling them as 'young carers'.

Don't assume I'm ok I carry more responsibility than you know

#BrainAwarenessWeek
#DontAssumeImOk



For young people going through a similar experience:

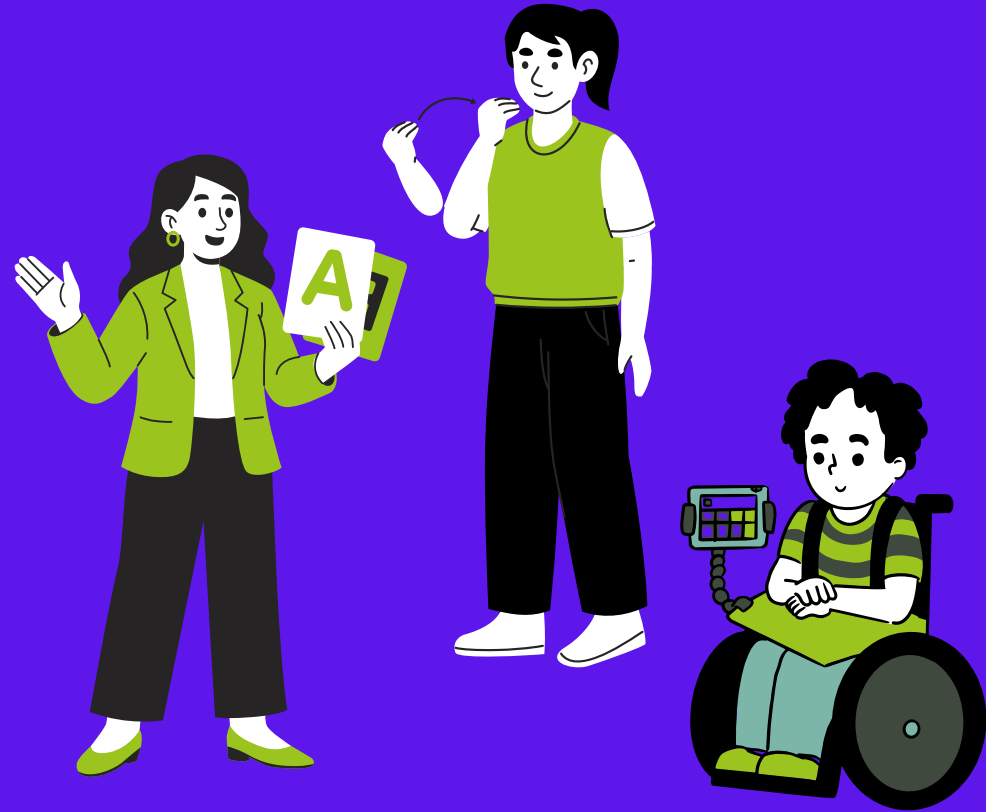
We see you. You are doing so well, and are so important to your families' lives, keep fighting for what you see, know, and feel, and ***know your voice is important too.***

Don't assume I'm ok I carry more responsibility than you know

#BrainAwarenessWeek
#DontAssumeImOk



Don't assume I'm ok



Include me in the conversation

#BrainAwarenessWeek
#DontAssumeImOk



Don't assume I'm ok

There has been a fair bit of anxiety around moving from the young people's service to the adults' service

Include me in the conversation

#BrainAwarenessWeek
#DontAssumeImOk





I do feel included in decisions about my health, I have considered genetic testing for Huntington's disease and have been supported really well in making decisions around this.

*No one has ever made a decision for me regarding this, but they have given me **information, resources and time to allow me to make the decision myself.***

Don't assume I'm ok include me in the conversation

**#BrainAwarenessWeek
#DontAssumeImOk**





*My mental health needs are being met by having the transition meeting, I have been worried about the change but I feel that the meeting will be reassuring to know that **despite moving to a new service; support is still available.***

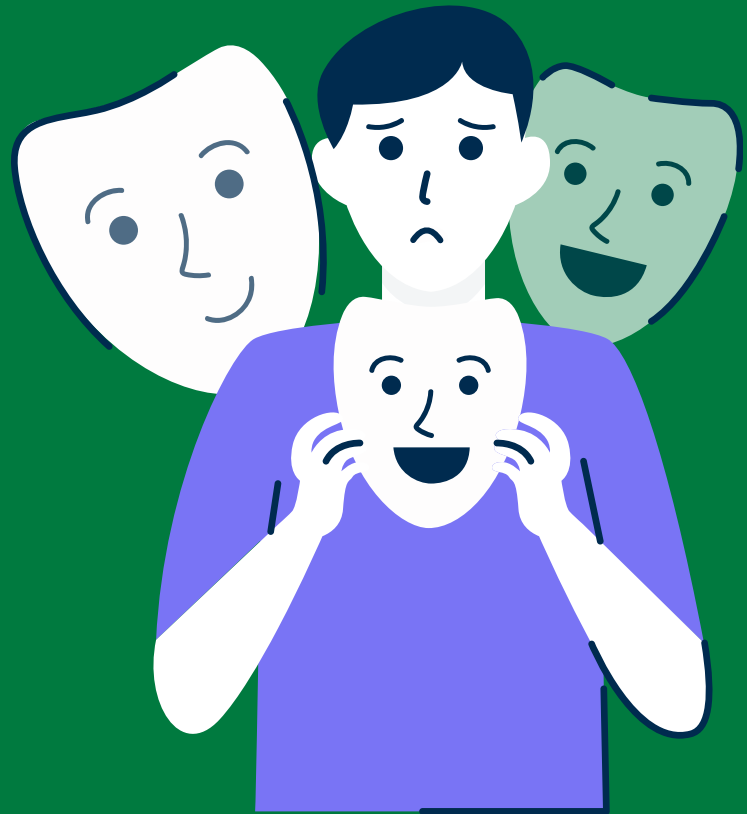
*Knowing that there is someone who understands Huntington's disease well, even if I don't get to speak to them often, is quite **helpful** and **reassuring** too.*

Don't assume I'm ok include me in the conversation

#BrainAwarenessWeek
#DontAssumeImOk



**Don't
assume
I'm ok**



**Just because
I look "ok"**

**#BrainAwarenessWeek
#DontAssumeImOk**



Don't assume I'm ok

*That's the one thing I
found really, really hard
to come to terms with,
people being like
"but you look fine"*

Just because I look "ok"

#BrainAwarenessWeek
#DontAssumeImOk





Out of everything, that's the one thing I found really, really hard to come to terms with, people being like **"but you look fine"**.

I look fine from the outside but on the inside you don't know how it's all working, you don't know where the gaps are, you don't know where the pain is. **Just because I look "normal" doesn't mean anything.**

Don't assume I'm ok just because I look "ok"

#BrainAwarenessWeek
#DontAssumeImOk



1 in 6
people live with
a neurological
condition

#BrainAwarenessWeek
#DontAssumeImOk



**Don't
assume
I'm ok**



**1 in 6 people live with a
neurological condition**

**#BrainAwarenessWeek
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