

There is understandably plenty of talk on Twitter about what not to say to those of us with chronic health problems, but what about the much harder questions of why people say them and what we actually want to hear? When I wrote my book on ME/CFS, addressing the painful subject of all the less than helpful things people had said to me helped me to understand better - and in some cases even have compassion for - the reasons why they can be said. (Some, of course, still feel completely thoughtless, selfish and unsupportive!)

People often say the first thing that comes to mind when faced with the uncomfortable reality of another's suffering ("But you're only young, you'll be fine). Sometimes they actually respond from a place of envy: feeling overwhelmed, tired, and craving what they perceive to be relief: being off work. Be careful what you wish for, being unable to work long term due to ill health is never an enjoyable situation.

Some comments that minimize the ill persons situation ('It can't be that bad') can come from not wishing to think about their reality - when you are seriously ill you face some of the worst life has to throw at you; learn to tolerate levels of pain and distress you could never have imagined; you face your own mortality; find out what it might feel like to be very old and learn that you are much stronger than you thought. People who haven't experienced such extremes not only lack this personal development, but also often harbour a very human and deep seated fear of illness, incapacitation and even death that they do not wish to think about. Someone with chronic illness can represent those things. The need to try and avoid this or 'help make it better' can result in what can be heard as really hurtful and dismissive remarks such as "have you tried resting?"

Bearing in mind it can be very difficult to articulate what a chronic illness feels like as the symptoms are often complex and changeable - here are some positive, supportive things you can say. Everyone needs compassion, to not be judged, to be heard and understood.

-“I don't know what to say / I'm not very good at this sort of thing” - being honest about your struggle to empathise is better than saying the first thing that comes into your head.

-“I'm really sorry that you're not well, is there anything you need me to know?”

-“I don't know anything about your illness, what do you wish people understood?”

-“I'm going shopping, can I get you anything” - offering practical help acknowledges difficulty without the need to discuss details.

-“What can I do to help / what would you like me to do?” - when you have been ill for a long time being asked how you are can be wearing, so offering help is a good alternative.

-“Do you want to tell me about it?/ I’d like to understand how you are”

-“I get really tired but I don’t know anything about your illness, what is it like?”

-“That’s a surprise to me because you look so well, how do you feel?”

So, next time you talk to someone whose life is severely affected by health problems, try to ask open questions that invite them to explain what life is like for them, rather than making assumptions. And if you are the one who is ill, know that sometimes the things people say that hurt you come from ignorance rather than maliciousness. Those that continually hurt may need a different approach.

For more on negotiating the difficulties of supporting a loved one with chronic illness see my book @11 published by Jessica Kingsley (2010) and follow me for more on living well with chronic health problems.