



PRACTICE

WHAT YOUR PATIENT IS THINKING

“Where there is life, there is hope”

When Sarah Ezekiel received a diagnosis of motor neurone disease, she became deeply depressed. Seventeen years later, she describes what helped her regain hope

Sarah Ezekiel

In April 2000, I was 34 years old, seven months pregnant with my son, Eric, and a full time mother to my daughter, Aviva. The last thing I expected was to develop motor neurone disease (MND). My doctor gave the initial diagnosis in a positive, helpful way. I was told that some people live a long time with MND and that some don't become too disabled. I decided not to do any research until after my son was born, but just two days after his birth I was horrified to read a newspaper article about a woman with MND who was campaigning for euthanasia because she hated her life.

Loss of hope

I was in shock and terrified. The thought of dying and leaving my children was unbearable. Life felt hopeless.

I needed support, but some healthcare professionals seemed more frightened of MND than I was and couldn't offer comfort. One walked into my bedroom where I was resting with my newborn and said I probably wouldn't see my children grow up.

I was referred to a counsellor, who said she couldn't help, but I could “cry on her shoulder” if I wanted. I think she felt that she couldn't do anything for me because MND is terminal. Everyone seemed to have given up on me and I felt suicidal. After a year I had lost most of my speech and movement and was unable to act on my feelings. Struggling to communicate was the worst part because I felt I'd lost my identity.

My marriage collapsed. I had custody of our children but life as a disabled parent was a struggle.

Getting my life back

I was given a leaflet for the MND Association at diagnosis, but was too scared to phone them. A friend called them in the end because she could see I was struggling. The MND Association has helped me financially, emotionally, and in every way it can. A visitor from the association referred me to my local hospice in 2001. Using the hospice gym made me feel that I was doing everything to keep my mobility and I still attend twice a week. The medical director took care of all of my needs and let me email him whenever I felt anxious.

Hypnotherapists helped with anxiety and taught me ways to cope.

Regaining my voice

Medical professionals with a respectful, positive attitude are important for my confidence. Recently a specialist spoke to me but looked at my carer. That was frustrating and made me feel inferior.

On the other hand, the hospice medical director respects my wishes even if he doesn't agree with them. I decided very early on after diagnosis that I wouldn't have a feeding tube if I had trouble swallowing. If I lose weight he suggests a feeding tube (jokingly) and I kick him, because I still can.

Accessing assistive technology (also known as augmentative and alternative communication, or AAC) in 2005 has allowed me to communicate and it has transformed my life. I now use “eye gaze” technology, which tracks my eye movements, and I'm able to do everything on my computer that able bodied people can do. I'd studied art and losing the use of my hands was devastating, but in 2012 I started making art with eye gaze.

I have now lived with MND for 17 years. I have raised my children, I am an artist, an award winning volunteer, and I am glad to be alive. Please believe, and let your patients know, however devastating the diagnosis, that where there is life there is hope.

What you need to know

- MND can be unpredictable and everyone progresses differently
- Even with a terminal diagnosis, with the right support, people can feel better and even hopeful about their situation
- Early referral to hospice care and providing assistive technology can transform lives

Education into practice

- Do you know how to help your patients with speech or movement loss access assistive technology?
- Consider reviewing how many of your patients with terminal diagnoses have palliative care involvement, and who may require referral to your local hospice team
- Hope means different things to different people. How can you help your patients with terminal illness find hope in their situation?

Further resources

MND Association www.mndassociation.org/

Sarah's website sarahezekiel.com/

Information about the correct referral pathway for AAC: www.mndassociation.org/aacpathway

Information about AAC www.mndassociation.org/aac

Information about voice banking www.mndassociation.org/voicebanking

Information (for people with MND) about speech and communication support www.mndassociation.org/speech

Competing interests: I have read and understood BMJ policy on declaration of interests and declare the following: none.

Sarah Ezekiel wrote this article using eye gaze technology (www.youtube.com/watch?v=f2ikTX8JxtE, www.youtube.com/watch?v=duujDhKb2EI).

Published by the BMJ Publishing Group Limited. For permission to use (where not already granted under a licence) please go to <http://group.bmj.com/group/rights-licensing/permissions>