“People who acquire disability may grieve their loss forever”

In this fast-living digital age there have been astonishing developments in the field of biomechanics, prosthetics and transplant surgery, as well as stem cell research, which has already shown tremendous results.

Yet for those of us with an acquired disability many of these developments offer little hope of a change to our conditions and how we live our daily lives.

I live in Essex, and the present statistics show that around 20% of the county’s population have a disability. I am one of them. I have been registered blind as a result of diabetic retinopathy since June 1993.

Am I still grieving? The simple answer is yes – no longer acutely, but I grieve for the loss of my sight.

Have I come across sufficient empathy and understanding of this long-term grief? I am sad to say this has been rare.

I was a nurse until I lost my sight, so it saddens me to experience efficient but often detached nursing. Other healthcare staff do not appear to appreciate the long-term psychological impact of sensory loss.

As nurses do you ever stop to consider how people with disabilities cope? Do you understand the psychological damage that a disability can cause?

For most people any permanent physical or sensory loss leads to grief that eventually abates but never goes away completely. I believe the stages mirror those that occur when someone close to you dies.

I have experienced the following: denial; “why me?”; disbelief; anger; depression; going through a huge and often lengthy painful dip; and eventually coming to a “working acceptance”.

Disability and grief

The inability to live normally never allows us to forget about our disability. For me – and others with visual impairment – grief results from the loss of the ability to live normally and undertake certain physical and sensory activities. We have lost easy access to leisure facilities and buildings, the written word, driving a car, going shopping, enjoying a movie and seeing beautiful sights or even colours.

I am still grieving all these losses.

Think also of the relatives and friends of the person with an acquired disability. Nurses have a vital role in helping relatives to understand how the grieving process can affect behaviour and may never go away completely. One thing is certain: after 20 years I still need understanding and empathy, as the grief and loss is still there and may be for the rest of my life.

No matter how long they have lived with it, someone like me, with an acquired disability, may not have come to terms with it. I have come across people who seem on the surface to have learnt to cope, but in reality have not.

The number of suicides among the disabled community is substantially higher than in the non-disabled population, which is a serious issue.

So the next time you encounter someone with an acquired disability, please bear in mind the loss that they have experienced and continue to experience, and its impact on them and those around them. And please help them in an appropriate and sensitive manner.

Klaus Kopp is registered blind and has diabetes with associated kidney damage.