

Huntington's disease

grief and bereavement



**Huntington's
Disease
Association**

Anticipatory grief

Huntington's disease progresses and changes over many years, meaning that people with Huntington's and their carers may have been living with the impact of the condition over a long time. They may have spent many years, or even decades, explaining Huntington's to other people and find it hard to do again at this time too.



Loss of caring role

Those who lose someone with Huntington's disease may have had a long time with an intense caring role - the loss of their caregiving role and the changes when they are bereaved can be particularly hard.



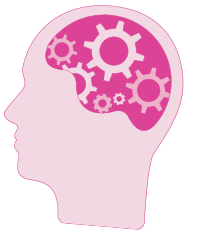
Impact of change and loss

The changes in Huntington's disease can involve different types of loss along the way both for the person with Huntington's disease and their carer. This could be jobs, driving or even relationships. Support around loss and grief is needed all the way along this journey.



Breaking down relationships

For some people, Huntington's disease can cause changes to thinking and behaviour, which may have impacted relationships over the years and, in some cases, caused strains in relationships, loss of contact etc - this can add additional layers to the response to grief and bereavement.



Previous loss

Huntington's disease is an inherited condition. This means people with Huntington's and their carers are likely to have previous experiences of loss, grief and bereavement within their family. How well someone has been supported with previous losses can impact on future losses.



Multiple losses

People impacted by Huntington's may experience multiple losses because of the inherited nature. When someone is bereaved, those impacted by Huntington's may be facing future losses as well - they might be at risk of Huntington's themselves, they may know they have the gene, be facing this with other family members or may be caring for someone else with the condition.

