

Bereavement support needs assessment

York JSNA

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Produced by City of York Council's JSNA group.

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Summary

This report looks at bereavement support service in York. Bereavement is a part of human experience, and will affect all of us at several points in our lives. Many people will find enough support through family and friends, however some will benefit from more formalised support as they work through their grief. There are some groups who are more at risk of needing this kind of support.

Overall, there is a good range of bereavement support services in York. This is supplemented by a very broad range of national bereavement support organisations. None of the services identified a significant increase in demand due to covid, but all identified that the lockdown measures had caused them to need to deliver support in a different way.

The recommendations in this report relate to ensuring that the bereavement support services available in York are sufficiently signposted and sufficiently well known by professionals who may be supporting family and friends with a death.

Death Statistics

Total Number of Deaths in York¹

Year	Deaths	rate per 100,000
2015	1806	928
2016	1810	913
2017	1825	910
2018	1902	934
2019	1866	907

Within the last 5 years, there has been a consistent 1800-1900 deaths per year within York, with the peak number of deaths occurring in 2018.

Age at death²

Age	Deaths
<1	3
01-09	1
10-19	0
20-29	8
30-39	20
40-49	42
50-59	104
60-69	175
70-79	452
80-89	622
90+	439

The data in the table above relates to deaths registered in York in 2019. The majority of deaths (33%) occur in the 80-89 age bracket. Only a small proportion of deaths, 74 (4.0%) occurred people aged under 50.

Causes of deaths³

Year	Cancer			Circulatory			Respiratory		
	York	Y&H	England	York	Y&H	England	York	Y&H	England
2015	27.5	27.4	27.4	27.1	26.7	26.2	13.9	14.1	14.2
2016	26.5	27.7	28.0	28.2	26.2	25.5	12.7	14.0	13.7
2017	28.3	27.4	27.6	25.5	26.1	25.1	14.1	13.6	13.8
2018	26.5	27.2	27.2	25.1	25.0	24.4	14.5	14.2	14.1
2019	29.0	27.4	27.9	25.2	24.8	24.4	12.0	13.9	13.6

¹ [Deaths registered by area of usual residence, UK - Office for National Statistics](#)

² [Death registrations by age group, local authority and ward, England, 2019 - Office for National Statistics](#)

³ [Palliative and End of Life Care Profiles - Data - PHE](#)

The table above details the percentages of all deaths by main underlying cause of death (all cancers, all circulatory diseases and all respiratory diseases). It shows the percentages by year, 2015 – 2019 and also compares York to the region (Yorkshire and Humber) and the rest of the country (England). There has been a downward trend in deaths from underlying cause circulatory disease, which has plateaued in recent years. This trend has been seen within York, regionally and nationally. Cancer and respiratory underlying cause has remained reasonably static both locally and nationally, however in the most recent year York has seen significantly lower number of respiratory underlying cause deaths.

Place of death⁴

Percentage of all deaths that took place in hospital (2019)					
Age of death					
	All	< 65	65-74	75-84	> = 85
York	42.3	34.3	43.9	46.5	41.2
Y & H	44	43.3	47.4	47	40.3
England	44.9	44	48.3	48.4	41.4

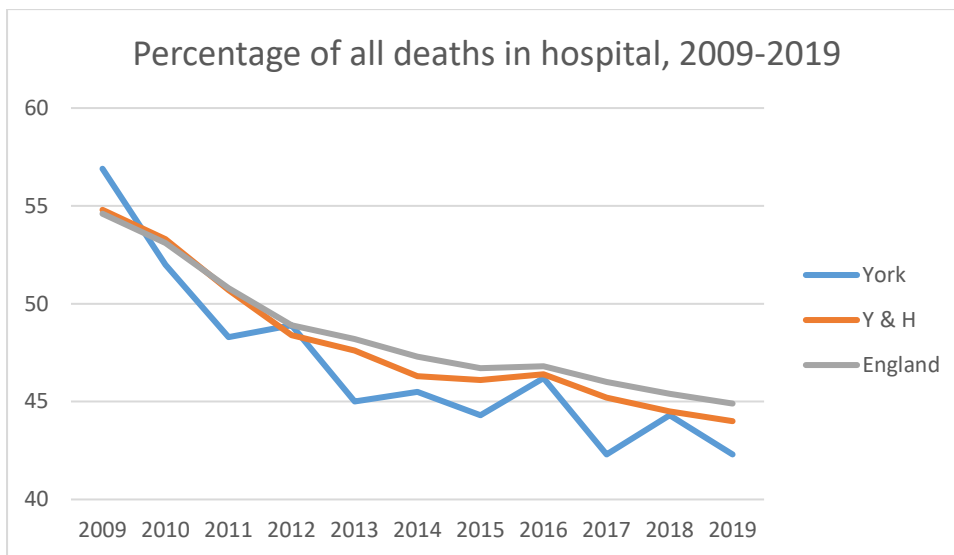
Percentage of all deaths that took place in care homes (2019)					
Age of death					
	All	< 65	65-74	75-84	> = 85
York	24.2	3.3	8.6	18.3	41.1
Y & H	22.2	2.7	8.6	20	38.5
England	22.5	3.1	9.1	19.4	37.5

Percentage of all deaths that took place at home (2019)					
Age of death					
	All	< 65	65-74	75-84	> = 85
York	23.6	36.8	31.2	25.9	14.9
Y & H	24.5	34.7	31	24.8	17.1
England	24.4	34.4	30.5	24.8	17.8

Percentage of all deaths that took place in a hospice (2019)					
Age of death					
	All	< 65	65-74	75-84	> = 85
York	8	16.7	15	8.3	2.5
Y & H	6.8	11	11.1	6.7	3.1
England	5.8	10.5	9.8	5.9	2.3

⁴ [Palliative and End of Life Care Profiles - Data - PHE](#)

Percentage of all deaths that took place in "other places" (2019)					
Age of death					
	All	< 65	65-74	75-84	> = 85
York	1.8	8.8	1.3	1.1	0
Y & H	2.4	8.3	2	1.4	1
England	2.5	8	2.3	1.5	1.1



From the above tables we can see a breakdown of where people died within 2019, in comparison to the rest of the region (Yorkshire and Humber) and the country (England). The places of death are either listed as hospital, care home, home, hospice or other place. The values are percentages of the total number of deaths, for all ages and broken down into separate age bands. In York, slightly less people overall die in hospital and at home, with slightly more deaths occurring in care home and hospices.

The chart shows a downward trend in deaths in hospital over the last 10 years, which is similar to that across the region and country. In 2009, 56.9% deaths occurred in hospital compared to 42.3% in 2019.

Child deaths

In the three years 2017-2019, 21 children in York died before their first birthday, in the same three year period, 13 children were stillborn⁵.

1 in 18 5-16 year old has been bereaved of a parent or sibling, that's one child in every average class⁶.

⁵ [Public Health Profiles - PHE](#)

⁶ [UK death & bereavement statistics | Child Bereavement UK](#)

Impacts of bereavement

It is important to note that there is no 'best practice' for health systems, employers, or individual organisations with respect of bereavement support.

Hospice UK promotes the view that whilst experiences of loss and grief are universal. Many people find sufficient support from family and friends. This group may also seek short term support, for example from their GP. This is often to check that their reactions are 'normal' and natural, and not a request for professional intervention.

By contrast, some people will find it more difficult to adjust to the loss, and will experience ongoing physical and mental health problems and persistent intense grief. There are some risk factors for this deeper grief response:

- The circumstances of the death (i.e. a sudden or traumatic death)
- The relationship with the person who has died (i.e. caring relationship or dependency)
- The circumstances of the person who is bereaved (i.e. existing ill health or social support)

Hospice UK says that this groups of people are at greater risk of ongoing and intense grief that has a sustained impact their physical and mental health, and who would particularly benefit from bereavement counselling. Hospice UK says that bereavement counselling should be targeted to individuals at risk of ill health, but that support from family, friends, and other compassionate listeners is sufficient for most people experiencing bereavement.

Experiences of the death

Experiences of the death, and feeling that the person had a good death, is linked to how the bereavement is processed. In 2015, 21,000 people responded to an ONS survey⁷ to share their experiences of bereavement. Predominantly, people spoke about deaths of older adults; 88% were over 65 at the time of death, their deaths were predominantly linked to CVD, or cancer. The sample did not include anyone who was speaking about a death of a young person, or a sudden death due to an accident or suicide.

As part of the survey, people were asked about the quality of communication they received from health care professionals in the last two days of life. The majority of people (about 80%) said that they understood the information given, were kept informed about changes in the dying person's condition or care, had enough time to ask questions, and were supported by health care professionals. Unfortunately, around 10% disagreed with all these statements, this was particularly true if the person died in hospital.

When asked whether they had talked to anyone from any support services since the death, most respondents reported that they had not, and did not want to (66%). However, 21% said that they had not, but would have liked to.

National evidence on bereavement linked to drug and alcohol deaths

Bereavement due to deaths from drugs or alcohol have additional layers of emotional and practical problems. In 2014 and 2015, the 'BEAD' project, led by AdFam and Cruse explored the experiences

⁷ [National Survey of Bereaved People \(VOICES\) - Office for National Statistics \(ons.gov.uk\)](https://ons.gov.uk)

of families and friends who had been bereaved through a death caused by drugs or alcohol in the UK. Though survey and phone interviews 100 families shared their experiences. Around half of respondents had lost a child, and a fifth had lost a spouse or partner. Others reported losing parents, siblings, other family members, only 3% of respondents reported losing a friend. The age of death was most commonly 31-40 years, nearly half of deaths were overdoses, but other deaths were linked to long term conditions or illnesses. Most were not receiving treatment at the time of their death. These national findings are broadly in agreement with the York JSNA drug related death needs assessment.

When asked about the support they received; respondents said that their own family and friends represented the most effective support, but immediately and in the long term. Experiences of professional services varied; but generally councillors, the coroner's office team, or GPs were rated as more effective and sensitive than health care professionals, social care professionals, or peer support groups. Many individuals felt that drug treatment services and the police did not offer any/enough support.

Experiences of judgement and stigma were common; from friends, family, neighbours, colleagues, as well as professionals in health service, social care, and the police. This was a significant barrier to asking for and receiving compassionate support.

National evidence on bereavement after caring

Around 6.8 million people in the UK are carers, though many of them do not think of themselves as such. Each year, around a third of these caring roles come to an end through bereavement.

Bereavement following a caring responsibility is unusual in that individuals experience a significant withdrawal of professional support from health services and social care services after the death. In many cases these contacts provided a social connection for the caring individual as well as the practical tasks necessary to support end of life.⁸ This is important because many people caring for someone at the end of their life become isolated. However, where there is adequate support and social connection before death, this is supportive after death⁹

Bereavement following a caring responsibility is also unusual in that levels of distress are often high before a person dies. Traditionally, there is a view that this is due to a degree of 'anticipatory grief' and preparation before death, but more recent research challenges this view. Carers who show higher levels of depression, anxiety, and pre-loss grief are more likely to have deeper and longer lasting grief symptoms after the death.

Finally, bereavement following a caring responsibility is unusual in that carers can also experience a sense of loss of purpose or identity after the death, as their caring responsibilities end. This can have an obvious emotional impact, and also financial impacts in respect of carers support benefits.

York Carers Centre Bereavement Support

York carers centre is able to continue working with carers for up to a year after the death of a person. However, the centre feels that many of their members are not aware of this. The carers

⁸ [Care-after-Caring.pdf \(nationalbereavementalliance.org.uk\)](#)

⁹ Leonard et al 2015

support workers are able to work with carers on practical elements like changes in benefits as well as emotional support on a one to one basis. The team received 'good grief' training in recent years. The service has good links to St Leonard's Hospice, and has directed many carers to seek further bereavement support through the hospice.

The service is looking for funding to have an end of life planning specialist within their team, this person would be able to offer advice on practical elements like power of attorney and benefits, as well as providing further emotional support to carers who have been bereaved.

National evidence on bereavement in Roma, Gypsy, Traveller communities:

People in Roma, Gypsy, Traveller communities have a shorter life expectancy than the general population and are ten times more likely to die by suicide. This means that GRT communities are more likely to have experienced recent bereavement and bereavement due to an unexpected death. Children in GRT communities are more likely to experience bereavement than children in the general population. Additionally, many communities are close-knit, with extended family members seeing each other on a daily basis, and supporting each other socially and practically. It is also common for GRT communities to have distinct funeral traditions.

Because of this, it is important that bereavement support services are sufficiently culturally aware, and accessible to people from different backgrounds.

National evidence on bereavement after a suicide

In 2020 University of Manchester published the 'from grief to hope' report, which presents the voice of over 7,000 people bereaved or affected by suicide in the UK¹⁰. Following a death, most respondents spoke about significant impacts; a fifth reported poor/worsening physical health, and a third reported poor/worsening mental health. 38% reported considering taking their own life, and 8% reported a suicide attempt. Other forms of risk taking, leading to substance misuse, relationship breakdown, and unemployment were also common.

60% of respondents did not access formal support after the suicide; though within this the experience is divided. 30% of respondents report getting enough support from family and friends, whereas the other 30% report not knowing what was available.

Respondents said that immediate, proactive support was important. Some participants were not always ready to seek or receive this help, but felt that information should be presented in an easily accessible format such as the 'Help is at Hand' support booklet, or an available person to contact for support when they were ready to receive it. After initial contact with agencies in the days and weeks following the death, participants indicated that ongoing follow-up support should be available with a specialist suicide bereavement support worker. Having access to support when they needed it was widely requested, with follow-up at 3, 6, 12 or 18 months after the suicide occurred.

¹⁰<http://research.bmh.manchester.ac.uk/cmhs/research/centreforsuicideprevention/fromgriefftohope/>

York response on bereavement after a suspected suicide

The York and North Yorkshire the coroner's office contacts the next of kin within a couple of days after every suspected suicide death. Referrals are then made to the bereavement support within the major incidence response team. However at present many families do not take up the offer. In 2020, there were 26 suspected suicide deaths in York, and 11 individuals referred to MIRT. This is relatively low, especially when considering that each individual death impact several close family members and friends. Families who did not initially engage have subsequently reported wishing they had accepted the offer.

Recommendation: For the coroner's office to continue with the ongoing work to explore how increase family engagement as this is a critical support both around bereavement and also to prevent future suicides. Recommend that the mental health partnership receive a report on this in the future.

The national peer support group "Survivors of Bereavement by Suicide" (SOBS) has the stated purpose of supporting and reducing isolation for adults who have been bereaved by suicide. This group is intended to support individuals in the months and years after the suicide.

Recommendation: For the SOBS resources to be included on the primary care referral support platform to enable GPs to give bereaved individuals greater choice about their support options.

York response following the death of a child

Deaths of children are often linked to long term conditions and a decline in health, deaths in children can also be due to sudden illness such as meningitis or occasionally through accidents.

After the death of a child, the Child Death Overview Panel for North Yorkshire and York meet within 48 hours. Before the meeting, parents are written to and told they can contribute via email or through a professional. The letter to parents includes the NHS bereavement support booklet 'when a child dies', but this correspondence does not include any additional signposting to local support groups. When the panel meets, one of the professionals is designated as the key contact for the parents, usually this is someone that the parents already have a relationship with.

The North Yorkshire and York panel usually direct parents to Martin House, where the team is able to provide bereavement counselling for the whole family. The child does not need to have been under the care of Martin House for the family to access bereavement support.

Recommendation: For the child death overview panel to use their routine written correspondence to parents as an additional opportunity to highlight local bereavement support, this may include Martin House and also St Leonards, as well as national organisations.

Support for bereaved adults in York

In the main, people who have been bereaved will find sufficient support through family and friends. A smaller proportion of people will seek out and require more formalised bereavement support.

Martin House is a hospice for children, this includes rest bite care and end of life care. The martin house bereavement team will support parents, and grandparents, following the death of a child. The child did not need to be a patient of Martin House. The bereavement counselling support now

provides therapeutic group interventions online, as well as in-person support for individual families. From March 20-March 21 Martin House received 90 referrals, from across Yorkshire, though not all families took up the offer. The service is open ended, meeting roughly fortnightly with bereaved individual.

The service accept referrals that relate to all types of child death, from expected end-of-life care deaths, to sudden and traumatic deaths. Recently, the service has expanded support to parents who have experiences still births and very late stage miscarriage. The service receive the majority of their referrals from St James' Hospital in Leeds. This may be because very unwell children are transferred to St James', however it may also represent a lower awareness of the Martin House offer among professionals working at York and Scarborough trust.

Recommendation: For Martin House to refresh their promotion and engagement work with York hospital trust and York GP practice groups, York mental health partnership to support where necessary.

Martin House are not aware of receiving and referrals from Roma, Gypsy, Traveller community members in York. This is perhaps surprising as the RGT population is more likely to have experienced the death of a child than the general population. There may be opportunity here to explore this further and consider the cultural accessibility of bereavement services in general.

St Leonards Hospice in York provide support to adults who have been bereaved. The person who has died does not need to have been a patient of St Leonards. St Leonard's bereavement support team is able to work with any adult in York who is experiencing bereavement. This is a 'listening service' and a safe space to talk; the service is keen to emphasises that grief is not an illness. They have an average caseload of 40 individuals at any time. In the main, most people have been directed to get in touch after a discussion with their GP. St Leonards is listed on the GP referral support platform in York. The service will work with individuals for 6-12 sessions, these sessions will appear on the GP record.

Support for bereaved children in York

National data shows that 1 in 18 school age children (aged 5-16) has been bereaved of a parent or sibling¹¹. There are three organisations in the York area that offer bereavement support to children.

Bereaved children support York (BCSE) was established in 2016 as a drop-in play session for children who have experienced bereavement. It has grown to a drop-in session that is accessed regularly by around 40 families, a parent support group, and 1-1 paid bereavement practitioners that offer support to children. The charity has good links with primary care and is featured in the referral support system, as well as good links with most York schools. Increasingly, the service is being contacted by CAMHS where there is a bereavement element to the mental health need. Previously the charity has delivered bereavement support training to some schools, and is looking to do his again.

St Leonards Hospice offers 1-1 bereavement support to children who were close to a patient who died under their care. Due to capacity, they are not able to support children with bereavement where the person who has died was not a patient. This service is run by a mix of paid staff and

¹¹ [UK death & bereavement statistics | Child Bereavement UK](#)

trained volunteers. The service provides a safe space for children to express their feelings, as well as advice and suggestions of resources to parents.

Martin House is also able to provide bereavement support to siblings of children who have died. The service generally only works with children whose parents are also engaged with the bereavement support team. Before covid, this was in the form of group sessions. Though covid, there has been some online group sessions for older children, and family based work for younger children. The service is hoping to reintroduce the children's group support soon.

Recommendations

For the coroner's office to continue with the ongoing work to explore how increase family engagement as this is a critical support both around bereavement and also to prevent future suicides. Recommend that the mental health partnership receive a report on this in the future.

For the SOBS resources to be included on the primary care referral support platform to enable GPs to give bereaved individuals greater choice about their support options.

For the child death overview panel to use their routine written correspondence to parents as an additional opportunity to highlight local bereavement support, this may include Martin House and also St Leonards, as well as national organisations.

For Martin House to refresh their promotion and engagement work with York hospital trust and York GP practice groups, York mental health partnership to support where necessary.

With thanks to:

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