



healthwatch
Darlington

Healthwatch Darlington
Bereavement Services Report
June 2019



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Introduction

Healthwatch Darlington Ltd (HWD) is a strong independent community champion giving local people a voice that improves and enhances health and social care provision on behalf of the people of Darlington. HWD believe that no matter who you are, where you live or what age you are, you do have a voice and you have the right for that voice to be heard.

Our Strategic Duties include:

Information Gathering

- Gathering views, experiences and needs of local people about their health and social care, focusing on those who are under-represented in decision making or face barriers to influencing the system.
- Gathering and monitoring other key information that tells us how the local health and social care system is working for people.

Influencing

- Influencing services and their commissioners to consider and act upon the views, experiences and needs we present.
- Championing the involvement of Darlington residents in the development and evaluation of services.

Informing

- Enabling people to get the most out of the current system by providing information about service provision, the rights people have in relation to their care, and opportunities they have to influence what care looks like.



Background to this work

Healthwatch Darlington are aware that there has been a recent change in the way bereavement services have been provided in Darlington. At the end of March 2018 the local branch of Cruse, the national charity that provides bereavement services and which has been providing services in Darlington for a number of years ceased to receive the temporary funding provided via Darlington Clinical Commissioning Group from the Better Care Fund. Cruse subsequently decided to withdraw its services from Darlington.

This report looks at the current situation in relation to bereavement services to see if there are gaps in provision. Healthwatch Darlington conducted an online survey aimed at people who have recently been bereaved and contacted GP Practices to understand their experiences of the current situation. We also contacted Darlington Clinical Commissioning Group and Cruse to understand the decision surrounding the withdrawal of funding and to ascertain if there is a solution in the provision of services to ensure local residents are fully supported if and when needed.

Survey

We conducted an on-line survey using Survey Monkey that was advertised in our weekly e-bulletin, on social media and at our outreach sessions from 23rd July 2018 to 30th September 2018.

61 people responded to our survey and the full results are in the appendix to this report. Of the 61 people who replied 55 reported that they were female and only one reported that they were male - 5 didn't reply to the question. The very strong female bias is an interesting fact and it is very difficult to extend any conclusions that might be drawn to males as they are so underrepresented. HWD cannot assume that men would answer the questions in the same way as women.

The respondents were either Christian (32 out of 61) or no religion (23 out of 61) or didn't respond (6). They reported that they were white (53 out of 61) or preferred not to say or skipped the question (8). Seven out of the 61 reported that they were disabled.



We asked first how much time had elapsed between the bereavement and the survey being completed. And there was a fairly even distribution between the time periods quoted in the question from 'very recent' (11 out of 61) but the largest group was between a year and five years (19 out of 61) and a few (9) were over five years.

We next asked if people had sought help from outside their immediate circle of friends and family and 18 said 'yes' to that question and all the rest said 'no'. Ten approached the GP first, five approached the hospice, two approached Cruse and one approached the Bereavement Officer at Darlington Memorial Hospital.

20 answered the question about the response of the person or agency approached of which 8 said that they were referred elsewhere whilst twelve were dealt with by the person or agency approached. Of the agencies to which people said they were referred there was a considerable range which included one to a funeral care provider, two to the hospice, two to Cruse, one to a counsellor and one to the psychiatric services provided by Tees, Esk and Wear Valley NHS Foundation Trust.

When we asked what kind of services were provided to them 18 answered of which 10 said that they were given a leaflet, seven said that they had counselling of which all but one had multiple sessions. One said that they joined a peer group of other bereaved people. When asked which was the most helpful only two mentioned the leaflet whereas eight mentioned counselling and nine found none of this helpful.

When asked how beneficial the help received was, nine found it beneficial or very beneficial whereas ten felt that it either made no difference or was even unhelpful (3) or very unhelpful (2).

We asked people who they would approach for help if they were sadly bereaved again. Out of 19 that answered four would go for counselling and the same number would rely on friends and family and also four would approach the GP. Three would seek help but didn't specify where from, two would approach Cruse and one each would approach the hospice or rely on self-help.

We asked those who didn't seek help for their reasons. 51 answered and the majority of reasons why people didn't seek help was because they were helping someone else through the bereavement (15), they felt able to cope (12) or they had a very supportive friend or family member (13). The other reasons people gave were too

busy (3), didn't know where to go (2), too apprehensive or embarrassed (2), didn't want to bother anyone (3) or worried about the possible cost (1).

For those who hadn't sought help they were asked if they thought help at this stage might be useful and if so, who they would approach. There was a range of answers. 36 answered this question of which fourteen said they wouldn't seek further help. Of those that would or might seek further help ten said that they didn't know who they would approach. Four said that they would seek counselling (of which two mentioned private or work-based counselling). Four mentioned seeing the GP and two mentioned the hospice.

In summary many seem to find friends and family a good resource, but people also seek help from the GPs, from the hospice, from counselling and a small number mentioned Cruse. HWD are concerned that for a small number help seems to be counterproductive, but this highlights the fact that clearly any help that is given requires a degree of expertise to avoid making things worse. Clearly this is a small sample and males are severely underrepresented and it is possible that their needs may be very different from the picture we are seeing here.



Guidance and Evidence

HWD looked for national guidance with reference to bereavement services and at any evidence in the literature that was able to tell us how effective such services are in helping the bereaved. There is very little to find surprisingly. The National Institute for Health and Clinical Excellence (NICE) which advises on drugs, operations and other treatments has not published any actual guidance on bereavement services but it has published a Quality Statement (1) which reads: *People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.*

In 2005 the Department of Health published a document, now archived; when a Patient Dies - Advice on Developing Bereavement Services in the NHS. (2) This is primarily advice to hospital trusts about developing services in dealing with the immediate needs of the friends and relatives of those who have died an expected or unexpected death in hospital. This includes arrangements for them to see the body, help with certification and registration of death as well as dealing with funeral services etc, rather than longer term support. At one point the document does say *“Trusts or individual hospitals may wish to consider if they could contribute to filling any gaps in local service provision”*. Suggestions for doing this include *“provision of bereavement support services not available elsewhere locally”* and *“joint funding of local community services either directly or through the supply of resources ‘in kind’ such as accommodation”*.

Evidence for the effectiveness of different forms of bereavement support is scanty. We looked at a systematic review of 74 different published studies produced by BMC Palliative Care (authors: Forte, Hill, Pazder and Feudtner) (3) They searched Medline and other databases for relevant papers. Eight related to the use of pharmacotherapy (medication). Thirty-nine featured counselling or support groups, twenty-five featured more intensive psychological therapies and seven looked at systems-orientated interventions. Overall their conclusion was that there was no consistent pattern, suggesting that intervention prevents the development of a serious depressive illness, except that treatment with medication, once it has arisen, can be effective and that is disappointing.

Is grief and mourning ever normal?

Death occurs to all of us; as we have families and friends, it is very likely that we will encounter loss during our lives and it will be an unpleasant experience, which can seem to us like an illness. However, there is a concept of normal grief and mourning which can still cause us to experience alarming symptoms such as hallucinations. The National Cancer Institute in the US, which is part of the US government's National Institutes for Health, has produced a very informative article (4) which explains normal and abnormal grieving and discusses options for treatment. It is not limited to death from cancer and the article is available in forms for professionals and patients. The link takes you to the patient's version but the professional version is linked to it. Others talk about complicated and uncomplicated grief - Shades of Grief (Scientific American) (5) and also the British Psychological Society in "The role of psychology in end of life care" (6).

What happens elsewhere?

We made enquiries through the Healthwatch network as to what happens elsewhere. An interesting example is from Healthwatch Liverpool, where Liverpool Bereavement Service (LBS) lost its core funding from the NHS via the local CCG in September 2017. That core funding was substantial - in the region of £46,000 per year. LBS decided to carry on and look for replacement funding. They do raise a considerable amount of money through fundraising from the public (and they have employed a professional fundraiser to help them). They also receive donations from three foundations and their Children's service (Oakleaf), which supports grieving children and young people, has received substantial support from BBC Children in Need. The Liverpool example would seem to suggest that in a large metropolitan area at least it is possible for a charity providing bereavement services to survive without public funding by using a combination of raising funds from individuals and from foundations and corporate entities.



Local resources in the Darlington area

1. General Practice

GPs and practice nurses are a major source of support to the bereaved, as borne out in our survey. GPs and practice nurses have the advantage of already being in contact with most of the people seeking help, although they may not have been involved with the care of the deceased person, who might have been registered with a different practice or might have died suddenly in hospital.

Where the bereaved person goes on to develop a psychological or even a physical illness, the GP is normally the first point of contact. Only doctors and nurse practitioners can prescribe drugs like antidepressants and drugs for anxiety and insomnia and for most people that means the GP practice unless the person is already in contact with psychiatric services.



Although psychological services can be accessed directly, the person requesting help, if they aren't referred by the GP, are first assessed by telephone. In some cases this may lead directly to a face to face consultation but sometimes they are referred back to the GP. However, many people choose to take a doctor's advice first and GPs are in a position to offer a degree of support themselves. Depending on their expertise and experience they may be able to provide something more akin to counselling, but that is very much hit and miss.

Generic GP training does not necessarily equip doctors to perform this role in the depth that may be required and even GPs who have the skills and experience may find that they cannot give the time necessary to the patient because of the many demands on their time. In the past, GPs have told us, they would often refer people to Cruse, the bereavement service but currently this is unavailable in the town of Darlington itself.

'Normal' bereavement can still be very distressing, but it is argued by some, including general practitioners that we have talked to, that it should not be medicalised and that where support is needed beyond what the person can get from within their social support network (and some, particularly the elderly, may not have much of a social support network) it is better provided from services other than those set up to deal with psychological illness.

2. The Hospice

St. Theresa's Hospice is able to provide support to family and close friends of those who have been treated by them during their final illness. We did write to them to ask if they were able to extend their service to those who might not have been in contact when the deceased was alive. They commented that, like other services, they were constrained by resources and they prioritised patients, relatives and carers in that order but on a case by case basis they might be able to provide support to others beyond that sphere.

When asked about their aspirations for the future they would like to take on a wider role in the community as perhaps a hub for bereavement services and a source of training. In the past they have been able to do this, hosting conferences and training events for those who work with the bereaved from a range of organisations but as things stand at the moment they are forced to concentrate on their core function, because of restricted resources.



3. County Durham and Darlington NHS Foundation Trust

In Darlington the Trust operates Darlington Memorial Hospital. As stated above in the Guidance and Evidence section, the Trust is obliged to provide a bereavement service but this is primarily a service for the newly bereaved whose loved one has just died in the hospital. Obviously, in the acute situation, there is a number of issues to be covered. The death may have been sudden and even the result of trauma. The cause of death may need explaining. The practical problems of a post mortem examination, certification, the possible involvement of the coroner and then dealing with a funeral director and planning the funeral are all issues that the hospital bereavement service can help with. They are also aided by the multi-faith chaplaincy service, who can help where the dying and bereaved wish for spiritual help. In relation to those who need longer term support, Noel Scanlon, Executive Director of Nursing for the Trust has replied as follows:

“The Trust has a Bereavement Support service to provide initial information and guidance to families following their loss. For additional longer term support the Trust signposts bereaved relatives to a range of voluntary agencies who

specialise in bereavement counselling which may be of a specialist nature. These include charitable services such as those provided by CRUSE, counselling services delivered by local hospices and counselling made available by the relatives' General Practitioner”.

Bear in mind, in connection with the reference to Cruse, that they do provide a service in areas covered by the Trust outside Darlington.

4. Cruse

Cruse is a national charity providing bereavement support and until March of 2018 they provided this in Darlington. On their national website (www.cruse.org.uk) they say that “Cruse supports bereaved people across the UK”. And at www.crusenortheast.org.uk , which is the website for the Tees Valley and Durham area a Darlington telephone number is given and it advertises a drop in session at their offices in Maude Street Darlington on a Monday afternoon, although they advise ringing first. However, when we checked in March, this drop-in service was not currently operational and Cruse were not offering services of any sort in the DL1, DL2 and DL3 post code areas, citing absence of funding. After checking with Cruse prior to publication of this report, we have been informed that their drop-in sessions on a Monday (2 - 4pm at their premises in Maude Street), which are advertised on their local website www.crusenortheast.org.uk , have restarted. Only self-referrals are accepted. Attendees are provided with Cruse's literature. No third party referrals are accepted and those needing more than can be offered in their drop in sessions (clients can attend more than once) are referred to their GP. Cruse say that the reason that they aren't able to offer more is because they haven't been able to secure alternative funding.

5. Generic counselling services such as Talking Changes.

Some bereaved persons are being referred to generic counselling services such as Talking Changes, who can be approached directly. In the first instance they offer telephone triage (www.talkingchanges.org.uk/getting-help/). Our survey did show that a number of people do find generic counselling helpful. However, there are problems with using such a service to deal with bereavement and grief.

We have been made aware, just prior to publishing the report, that Talking Changes is planning to increase the scope and accessibility of its service to specifically include bereavement counselling. We will be monitoring how effective and timely this is in filling the gap left by the absence of other services particularly in those people who require support at level 2 (i.e. requiring emotional support primarily rather than therapy).

Firstly, grief in the face of bereavement is normal (ref. National Cancer Institute, part of the US Government's National Institutes for Health, in its information leaflet on bereavement says: "*Grief is the normal process of reacting to (the) loss*" (4) and in most cases it doesn't represent an illness. Counselling services are primarily there to help those who have a mental health issue. There is a potential for bereaved persons to develop a mental health issue, such as depression, especially if they are unsupported, and in that instance a generic counselling service or even psychotherapy and possibly medication may be required. However, it is not inevitable, except perhaps where the person already has mental health issues or where the death has been particularly traumatic.

A generic service may have a waiting list and there may be a significant delay before the person can be seen. However, the service has told us that they do make early telephone contact. GPs have told us that persons referred for generic counselling have often either reached the stage where they no longer feel in need of help by the time that they receive an appointment, or the GP has felt that medication was required, even though it was the initial intention to try to avoid a prescription for medication such as an anti-depressant.



6. Private counselling or psychotherapy.

Private counselling or even psychotherapy is always an option and some of our responders have indicated that they have received this through coverage provided by their employer. However, although this can be very helpful, it can create barriers due to the cost of the service, so unless it is provided by an employer or private healthcare insurance policy it isn't a solution available to everyone.

7. Services for death in childhood, neonatal death, stillbirth and miscarriage.

Whilst this area is really outside the scope of this report, we have had this response which we mention here for completeness from County Durham and Darlington Foundation Trust in respect of support for families suffering miscarriage, stillbirth and neonatal death:

“County Durham and Darlington NHS Foundation Trust Maternity and Gynaecology service do provide a pathway of support for women and their families that experience loss during pregnancy and in the early days of life. Our service provides support to the family in many ways including guiding them through the decisions required with regards post mortems and tests, cremation or burial etc. In addition, our teams are very experienced in supporting families with photographs and creating memories. Our service offers counselling to women who have lost a baby at any stage of pregnancy and families that have had a termination for abnormality.”

The Trust is also involved with a project to improve its services, which is a national project led by SANDS, the charity dealing with bereavement due to stillbirth and neonatal death.

The project has the following aims:

- Increase in training for staff working with the service including gynaecology,
- Development of the existing team to ensure sustainability and quality care in bereavement,
- Development of new bereavement rooms in both acute suites including gynaecology (50K secured at present).
- Development and launch of bereavement charity ‘Forever loved’ in collaboration with Communications and CDDFT Charity.
- Development of ‘the offer’ with regards the counselling available and the introduction of support groups for: early pregnancy, stillbirth & neonatal Death and Rainbow babies (babies born after a previous pregnancy loss).

8. On line help

There are excellent sources of information available on line if information about the grief process is what is mainly required. People have described grief as being

bewildering and even frightening and explanations as to what is 'normal' can be very reassuring.

This is not an exhaustive list, but the following are very comprehensive and authoritative:

<https://www.psychologytoday.com/us/basics/grief>

<https://www.nhs.uk/conditions/stress-anxiety-depression/coping-with-bereavement/>

Conclusions

Dr A Arthur at the University of Nottingham produced a paper for the Department of Health looking at the literature available in relation to bereavement services and produced a set of recommendations. The document is archived (7) so does not necessarily represent official policy. The full set of recommendations can be found there but we believe the following are particularly pertinent:

1. *Attention should be paid to ensuring universal and equitable access to first level bereavement services* to facilitate a natural self-selection process through to more intensive bereavement interventions for those at greatest need and who are most likely to benefit*
2. *Provision can be loosely categorised into three levels of intensity:*
 - a) *acknowledgement and information based services;*
 - b) *one to one support and/or peer support; and*
 - c) *more intensive therapeutic and structured bereavement interventions for more complex grief reactions.*
3. *All those who are recently bereaved need to be provided with practical information needed in the initial period following the loss of a loved one that clearly points them to further services as required regardless of the place of death. Where possible, information should be self-contained.*
4. *Certain groups may face real problems in accessing services and information about bereavement. The gate-keeping role that parents play in children's access to bereavement services should be acknowledged and addressed by targeting information about services and support directly at children where possible.*
5. *Acknowledgement of the death by an appropriate member of health staff (hospital and/or primary care) should be standard practice undertaken with care*

and sensitivity to avoid the appearance of tokenism. Offers of further contact with the bereaved person need to be conveyed in such a way that it is perceived as genuine and easy to act on.

- 6. Bereavement should not be over-medicalised. The success of organisations like Cruse Bereavement Care may be partially due to its strong identity within the communities that local branches serve. This reflects most people's desire to get support from their social networks.*
- 7. Frontline health, education and social care staff need a basic understanding and awareness of grief reactions. This is needed to give these staff the confidence to provide the care that many say they lack. This will promote continuity of care for the bereaved. Joint training of professional and voluntary service providers may promote closer integration across these sectors.*
- 8. Comprehensive pathways can bridge gaps in services but should not be overly complex for service providers and recognise that entry and exit occurs at various points depending on the nature of the death and how that death is responded to.*
- 9. There needs to be greater transparency through documentation and audit of the provision, uptake and costs of bereavement services, particularly outside of hospice services such as acute trusts.*
- 10. In England many deaths occur in care homes, but relative to hospices there is a disproportionate lack of attention to bereavement care. This is an area for future research and service development.*

The report also looks at Need, Provision, Effectiveness and Cost. It notes that there is a dearth of information about cost effectiveness but there is nevertheless evidence that interventions, which should not be universal across the board but selective, can be cost effective if delivered by trained volunteers, but it points out that the use of volunteers is not without cost. Also addressing the need for and design of bereavement services is a joint report by Cruse nationally with the Bereavement Services Association. (8).

How to implement services in Darlington that achieve these aims?

- Our study shows that a service is needed and appreciated by people who are bereaved and although many people manage to cope with the help of social support, some do need additional help.
- GPs in Darlington have confirmed that the need isn't always being met satisfactorily because of the absence of a dedicated bereavement support service. This puts the onus back on the GP quite often to support people as best they can or requiring a referral to a psychological service. The latter is more appropriate for complex grief reactions but this too is unavailable in the short timescale which is the ideal.
- Statutory funding does not appear to be available at present for a dedicated bereavement service in Darlington. Understandably, public sector funders such as the Darlington CCG and Darlington Borough Council need to concentrate funding in areas where there is either direction from NHS England & Central Government or where there is evidence of efficacy, especially if it is likely to reduce expenditure in other areas.
- However, from our findings, it is evident that what is in place now is not meeting the undoubted demand for such a service from those bereaved people who seek it. Consequently, people are left waiting for long periods for what is available from a generic counselling service and in some cases are receiving medication which might otherwise have been avoided. Prior to its withdrawal from this role in Darlington, Cruse satisfied at least some of this demand.
- Clearly it is for Cruse to decide whether it is feasible for them to operate in Darlington without public sector funding, but we have established that there is no bar to them operating, other than a financial one.
- The Liverpool experience has demonstrated that, at least in their case, when statutory funding was withdrawn, sufficient funds were found from other sources to enable a service to continue and this funding came from both individuals and charitable foundations.



Recommendations

Healthwatch believe there are three levels of need for people who have been bereaved and there are numerous stakeholders in this issue including every member of the public living in Darlington who may be bereaved or could become bereaved at any time. Also businesses, charities and the health and social care sectors all have a stake in a satisfactory solution to how these needs can be met. We recommend the following:

Level 1

A basic understanding and awareness of grief reactions in the public, private and voluntary and community sectors is needed in Darlington, due to the lack of provision for our residents. It is the responsibility of all organisations provided they are given the correct tools. Generic material, such as a leaflets, reassuring people of the symptoms of grief and what is “normal” can be helpful, not just for the bereaved but for family, friends and work colleagues. At the moment we have online resources that signpost people to a service that does not exist in Darlington. Perhaps the Local Strategic Partnership can take this to Board level and discuss a solution in which their business and community stakeholders can help to pool resources for a Darlington leaflet and basic bereavement training.

Level 2

We have established that grief is an emotion rather than a mental health issue for most people. Counselling services, set up primarily to deal with mental health issues, may not therefore be appropriate at this level but we do note that Talking Changes is planning to improve access and scope of its services to incorporate traumatic life events such as bereavement and that is to be welcomed. However, we will be monitoring the situation to see if their service fits into this level of support in a timely fashion and with sufficient availability, or whether it is primarily aimed at those who require support at level 3.

There probably will remain a need, outside the mental health sector, for some bereaved people and we know that this can be provided by appropriately selected, trained and supported volunteers. Though not without any cost, this type of support can be very cost effective. Perhaps the CCG and local authority need to discuss this

at ICP level, in order to pool resources for a relatively small amount of funding to support in addition to statutory provision, additional resources in the voluntary sector.

Level 3

This level starts to cost money for health and social care services, as a person's grief, when not given the right help and support at the right time, can manifest itself into a mental or physical health issue, which needs expertise. This level can be avoided if level 1 and level 2 support is instigated appropriately. More people are going to be pushed to this level, creating more expense than providing resources for the initial guidance and training that is needed at the start of the grieving process. Perhaps commissioners, providers, funders and key stakeholders in Darlington need to take note of the levels of bereavement support that is needed for our community and understand how much the provision is valued by those that need it most.



Darlington CCG Feedback

Thank you for sharing the draft Bereavement Services Report with the Clinical Commissioning Group. It's an important topic and the report was interesting and easy to read.

CCG colleagues have reviewed the draft report and as requested have provided comments.

The report states that the organisation ceased to receive funding from Darlington Clinical Commissioning Group which resulted in Cruse withdrawing its services from Darlington. We ask that this could be amended to provide further clarity, stating the organisation

'ceased to receive the temporary funding provided via Darlington CCG from the Better Care Fund. Cruse subsequently decided to withdraw its services from Darlington.'

We noted that bereavement support from NHS Foundation Trusts is in place as we would expect. In addition, it is reflected in the report that there is provision in place for Darlington patients presenting with bereavement via the IAPT service, Talking Changes, commissioned by Darlington CCG.

Thank you again for sharing this draft report with us.



Michael Houghton

Director of Commissioning, Strategy and Delivery (Locality Commissioning Director Hartlepool and Stockton - on -Tees CCG & Darlington CCG)

Acknowledgements

Healthwatch Darlington would like to thank everyone who completed the surveys. Your comments and experiences of local bereavement services are so appreciated and will help us to influence at a strategic level to ensure the planning and delivery of services meets your needs and those of your family and friends.

Bereavement references:

1. Quality Statement re Bereavement from NICE
<https://www.nice.org.uk/guidance/qs13/chapter/quality-statement-14-care-after-death-bereavement-support#quality-statement-13>
2. Developing a Bereavement service - DOH.
<http://www.hscbereavementnetwork.hscni.net/wp-content/uploads/2014/05/When-a-patient-dies.-Advice-on-Developing-Bereavement-Services-in-the-NHS-October-2005.pdf>
3. Bereavement Care Interventions - A Systematic review. Despite abundant bereavement care options, consensus is lacking regarding optimal care for bereaved persons.
Authors: Amanda L Forte, Malinda Hill, Rachel Pazder and Chris Feudtner
Citation: *BMC Palliative Care* 2004 3:3
Published on: 26 July 2004
4. Grief Bereavement and Coping with Loss. NIH National Cancer Institute. (Available in patient and professional versions) <https://www.cancer.gov/about-cancer/advanced-cancer/caregivers/planning/bereavement-pdq>
5. Shades of Grief - Scientific American. Discusses the implications of the two major innovations in DSM 5. Firstly that there is such a condition as complicated grief, characterised by longing for the deceased and other symptoms and which is distinct symptomatically and neurophysiologically from depression and possibly amenable to a cognitive approach and depression being diagnosable at two weeks (previously the bereaved had to wait two months) - the latter being highly controversial and really more relevant in the US where the DSM determines insurance payouts. <https://www.scientificamerican.com/article/shades-of-grief/>
6. The role of psychology in end of life care - The British Psychological Society. A report by the British Psychological Society. (Classifies grief as uncomplicated or complicated and reserves the role of psychology for the latter. Outreach is discouraged as it may impair adaptation to loss and in reach by those who identify themselves as having a problem is encouraged).
7. Bereavement services - a synthesis of the literature produced by Dr A Arthur and Colleagues at Nottingham University commissioned by the Department of Health. <https://webarchive.nationalarchives.gov.uk/20130502195344/https://>

www.gov.uk/government/publications/bereavement-care-services-a-synthesis-of-the-literature

8. Bereavement care service standards - Produced by Cruse nationally in corroboration with the Bereavement Services Association.
https://www.cruse.org.uk/sites/default/files/default_images/pdf/Documents-and-fact-sheets/Bereavement_Care_Service_Standards.pdf

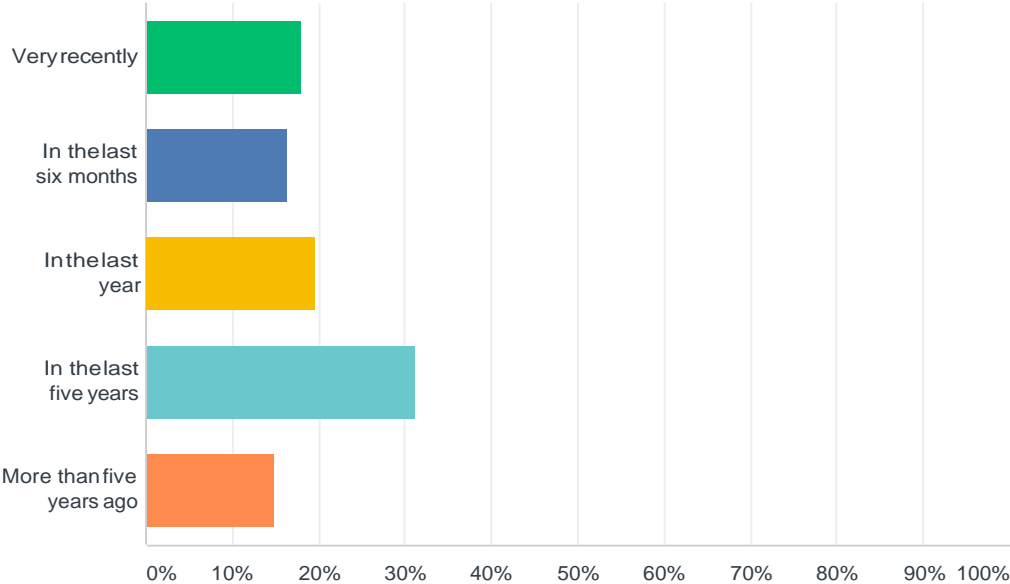
Other weblinks, articles and booklets not directly referenced in the text but providing background:

- a) <https://www.psychologytoday.com/us/conditions/bereavement>
Discusses various aspects of bereavement.
- b) <https://www.talkingchanges.org.uk/getting-help/>
Discusses how to contact Talking Changes for help.
- c) End of Life Care Strategy - Department of Health
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf
- d) When a patient dies - advice on developing bereavement services in the NHS Department of Health: <http://www.hscbereavementnetwork.hscni.net/wp-content/uploads/2014/05/When-a-patient-dies.-Advice-on-Developing-Bereavement-Services-in-the-NHS-October-2005.pdf>
- e) Early intervention following Trauma - Atle Dyregrov
<https://www.coe.int/t/dg4/majorhazards/ressources/virtuallibrary/materials/norway/EarlyIntervention.pdf>
- f) Risk of suicide, deliberate self-harm and psychiatric illness after the loss of a close relative: A nationwide cohort study. Guldin et al
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5428185/>
- g) Literature Review on Bereavement and Bereavement Care - **Book** · January 2006
with 887 Reads DOI: 10.1080/02682620708657678 Publisher: 0268-2621
Publisher: Joanna Briggs Collaborating Centre for Evidenced Based Multi-professional Practice
https://www.researchgate.net/publication/235935346_Literature_Review_on_Bereavement_and_Bereavement_Care

Appendix 1 - Bereavement Survey Results Summary

Q1 How long ago was it that you suffered a bereavement?

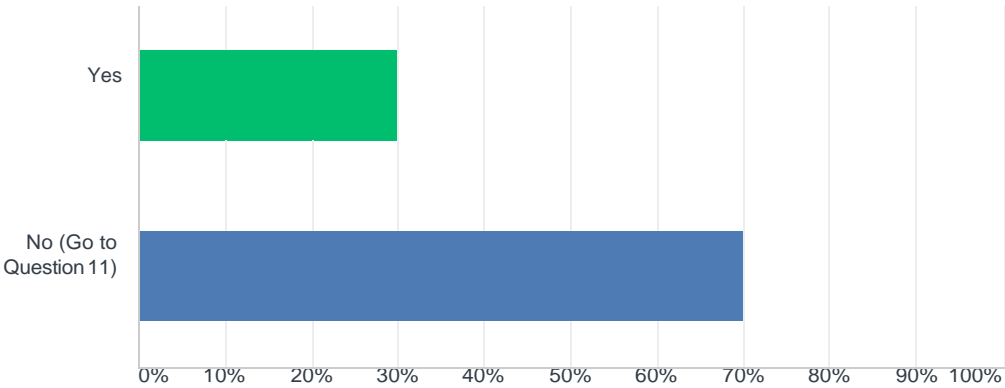
Answered: 61 Skipped: 0



ANSWER CHOICES	RESPONSES	
Very recently	18.03%	11
In the last six months	16.39%	10
In the last year	19.67%	12
In the last five years	31.15%	19
More than five years ago	14.75%	9
TOTAL		61

Q2 At the time of your bereavement did you seek help from anyone outside the family or your circle of friends to deal with your loss?

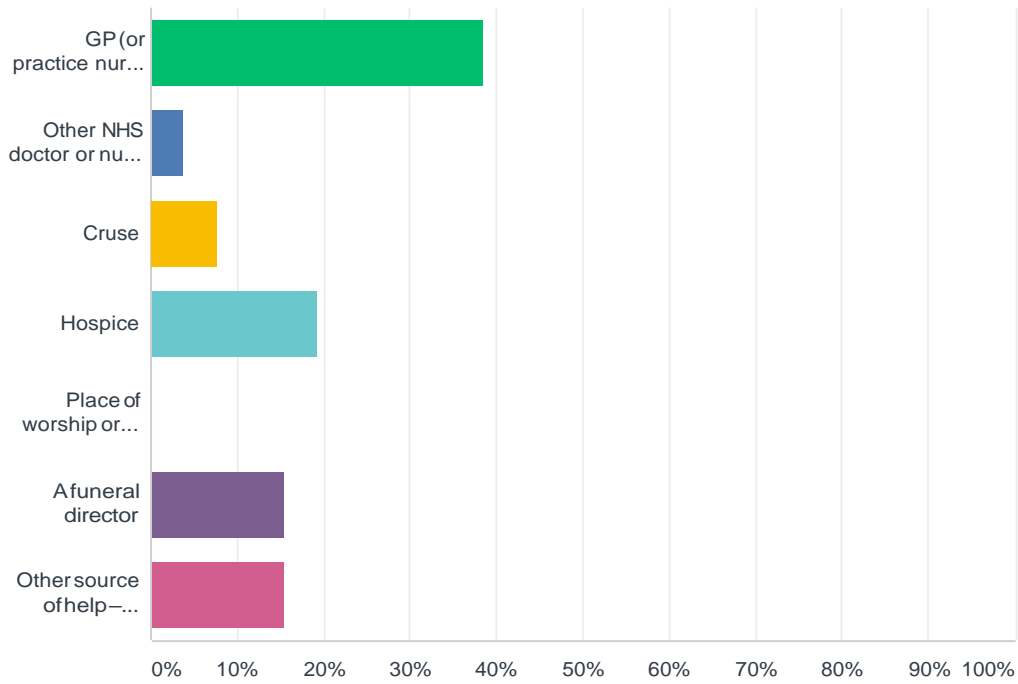
Answered: 61 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	29.51%	18
No (Go to Question 11)	70.49%	43
TOTAL		61

Q3 Who did you approach first?

Answered: 26 Skipped: 35



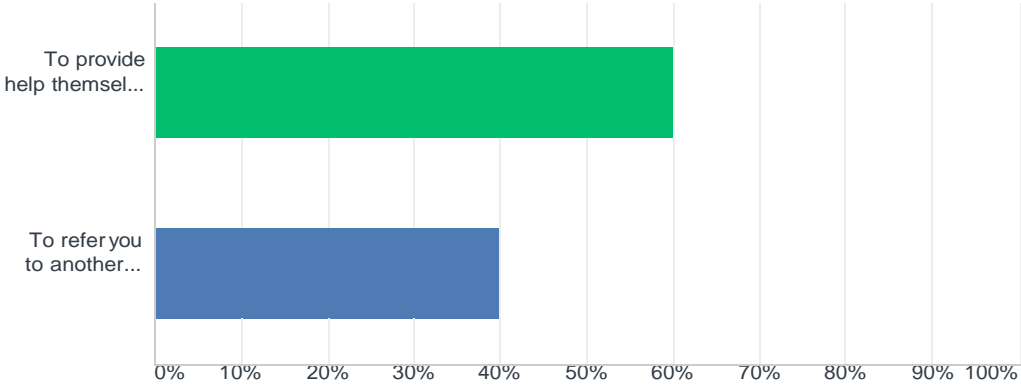
ANSWER CHOICES	RESPONSES	
GP (or practice nurse)	38.46%	10
Other NHS doctor or nurse	3.85%	1
Cruse	7.69%	2
Hospice	19.23%	5
Place of worship or religious adviser	0.00%	0
A funeral director	15.38%	4
Other source of help – please describe here	15.38%	4
TOTAL		26

Q4 Were you contacted first by your GP or another agency and invited to get in touch? If so, by whom?

Answered: 23 Skipped: 38

Q5 What was the response of the person or agency that you approached?

Answered: 20 Skipped: 41



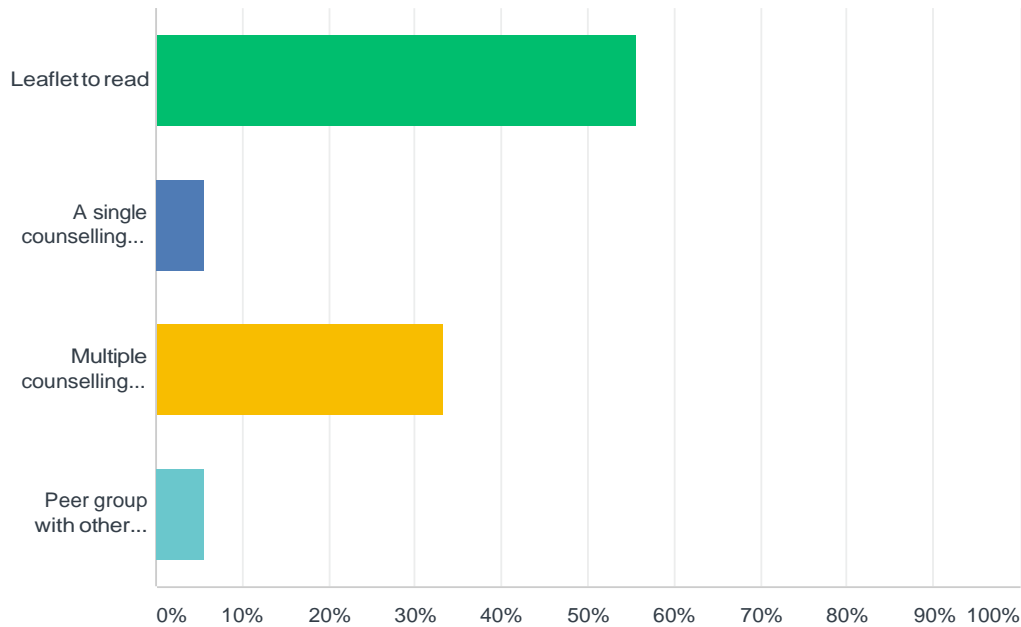
ANSWER CHOICES	RESPONSES	
To provide help themselves (Go to Question 7)	60.00%	12
To refer you to another agency.	40.00%	8
TOTAL		20

Q6 Please name the agency or person to which you were referred:

Answered: 14 Skipped: 47

Q7 What type of help did you get from the person or agency that you initially approached and/or the person or agency to which you were referred? (Tick all that apply).

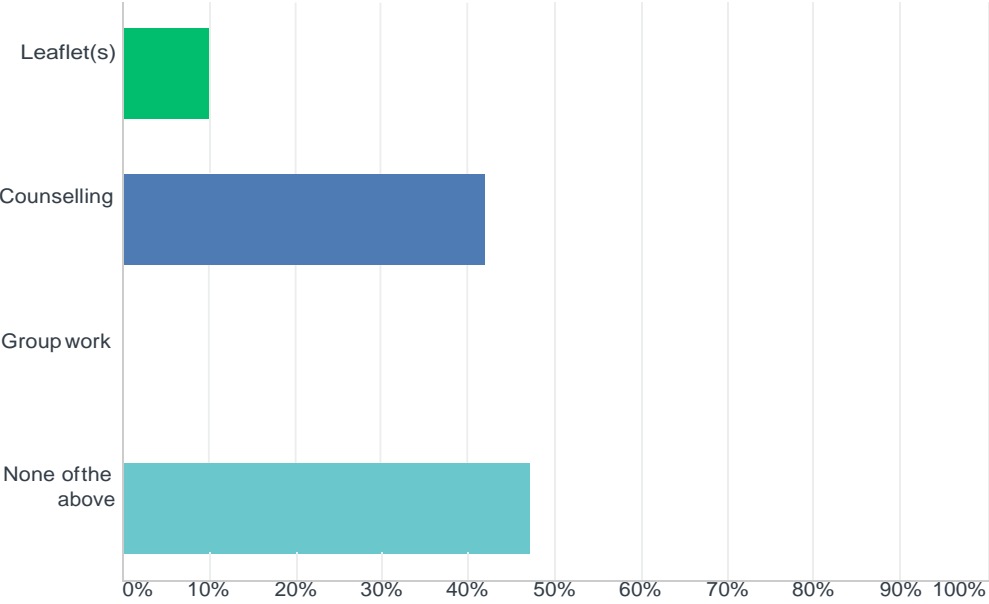
Answered: 18 Skipped: 43



ANSWER CHOICES	RESPONSES	
Leaflet to read	55.56%	10
A single counselling session	5.56%	1
Multiple counselling sessions	33.33%	6
Peer group with other people in a similar situation to yourself	5.56%	1
TOTAL		18

Q8 In reference to Question 7, which did you find the most help? (Tick one only)

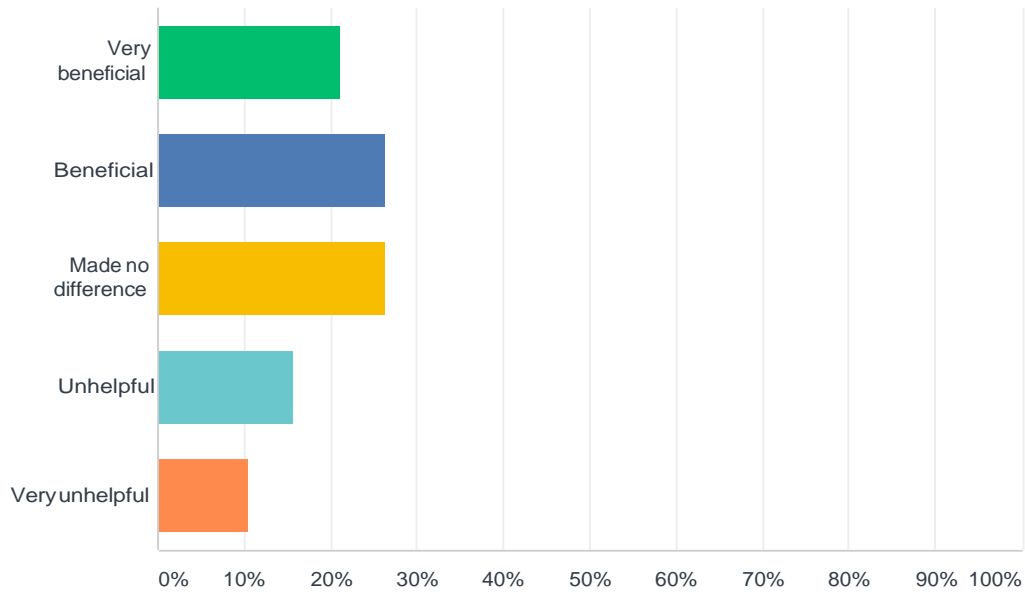
Answered: 19 Skipped: 42



ANSWER CHOICES		RESPONSES	
Leaflet(s)		10.53%	2
Counselling		42.11%	8
Group work		0.00%	0
None of the above		47.37%	9
TOTAL			19

Q9 Did you feel that the help that you received was:

Answered: 19 Skipped: 42



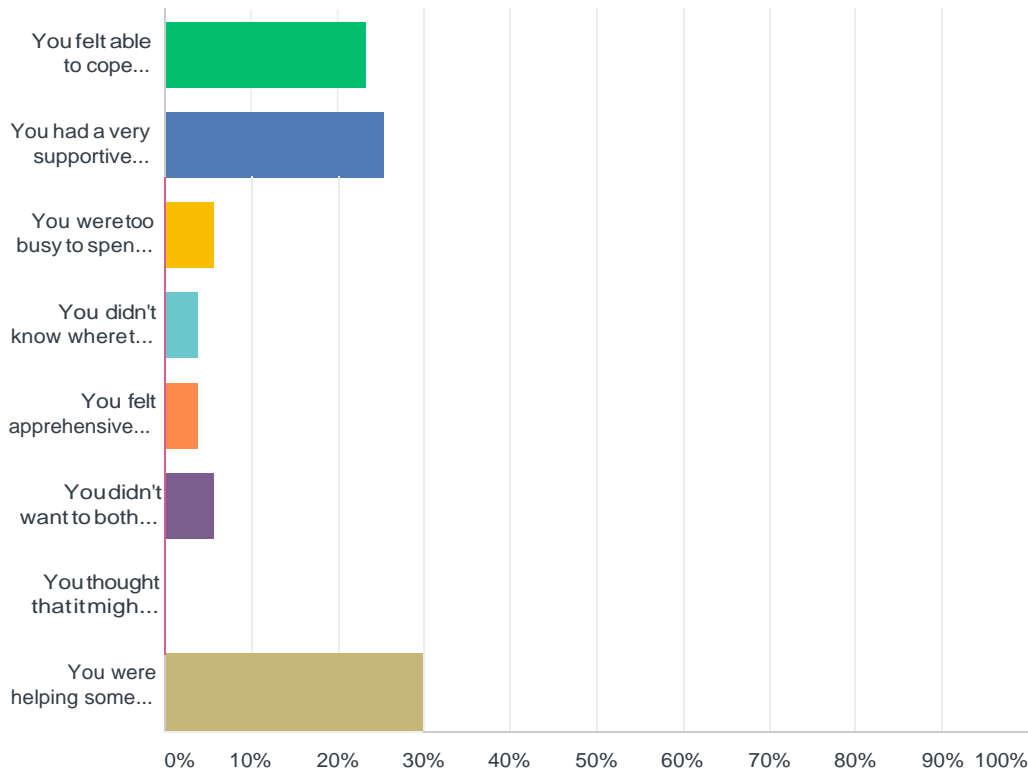
ANSWER CHOICES	RESPONSES	
Very beneficial	21.05%	4
Beneficial	26.32%	5
Made no difference	26.32%	5
Unhelpful	15.79%	3
Very unhelpful	10.53%	2
TOTAL		19

Q10 If you or a friend were sadly bereaved again what would you do? What would you recommend them to do? (Please answer, then go to Question 13)

Answered: 18 Skipped: 43

Q11 As you didn't seek outside help for your bereavement, was this because:

Answered: 51 Skipped: 10



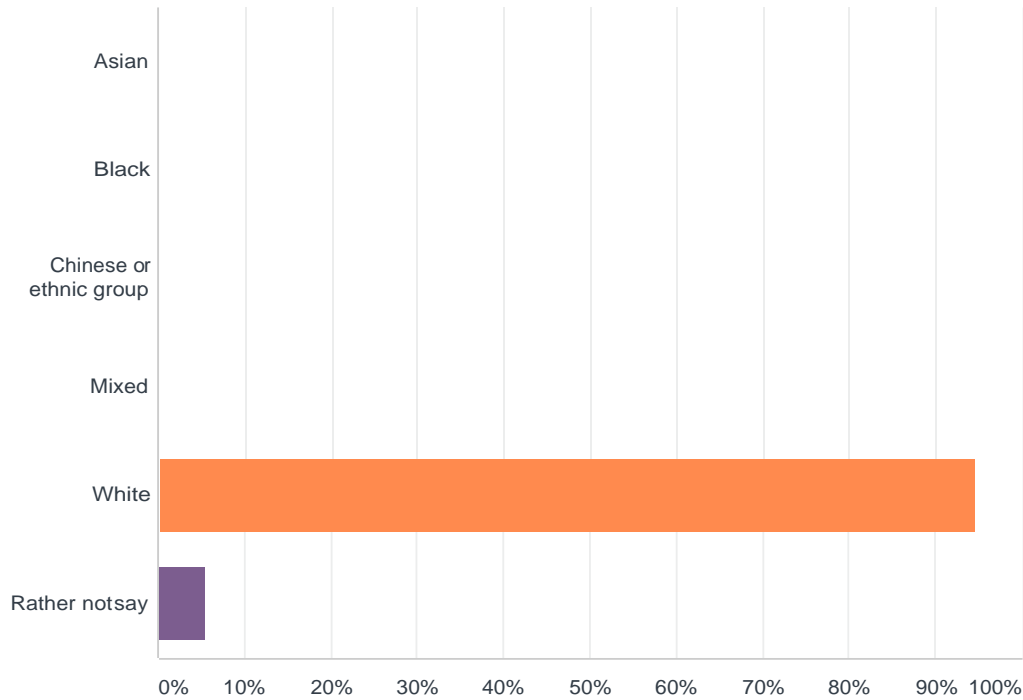
ANSWER CHOICES	RESPONSES	
You felt able to cope yourself	23.53%	12
You had a very supportive friend or family member	25.49%	13
You were too busy to spend time seeking help	5.88%	3
You didn't know where to go for help	3.92%	2
You felt apprehensive or embarrassed about seeking help	3.92%	2
You didn't want to bother anyone	5.88%	3
You thought that it might cost money that you couldn't afford	1.96%	1
You were helping someone else cope and you put your own interests on the 'back burner'	29.41%	15
TOTAL		51

Q12 Do you feel that at this stage it might still help to see someone? If so, who would you approach?

Answered: 35 Skipped: 26

Q13 Please state what you consider your ethnic origin to be. Ethnicity is distinct from nationality and the categories below are based on the 2011 census in alphabetical order:

Answered: 56 Skipped: 5



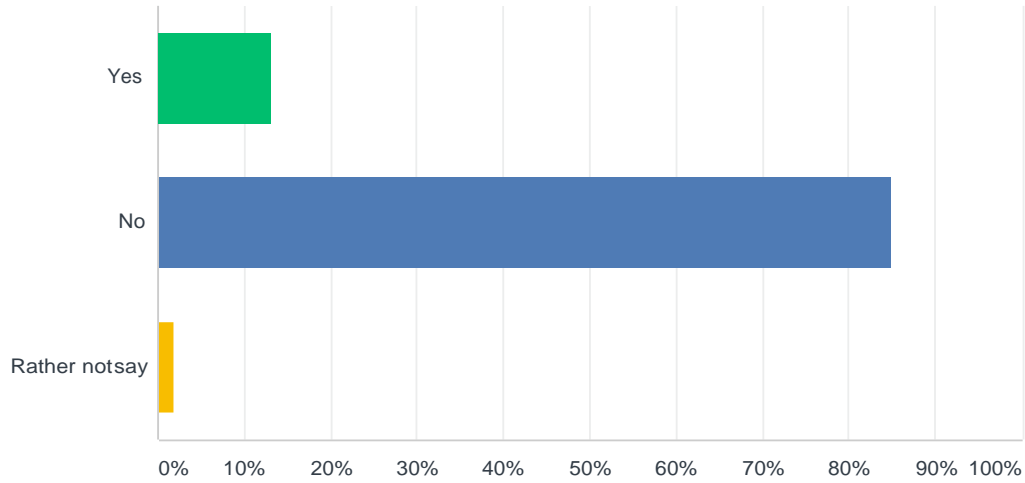
ANSWER CHOICES	RESPONSES	
Asian	0.00%	0
Black	0.00%	0
Chinese or ethnic group	0.00%	0
Mixed	0.00%	0
White	94.64%	53
Rather not say	5.36%	3
TOTAL		56

Q14 Age:

Answered: 56 Skipped: 5

Q15 Do you consider yourself to have a disability according to the above definition?

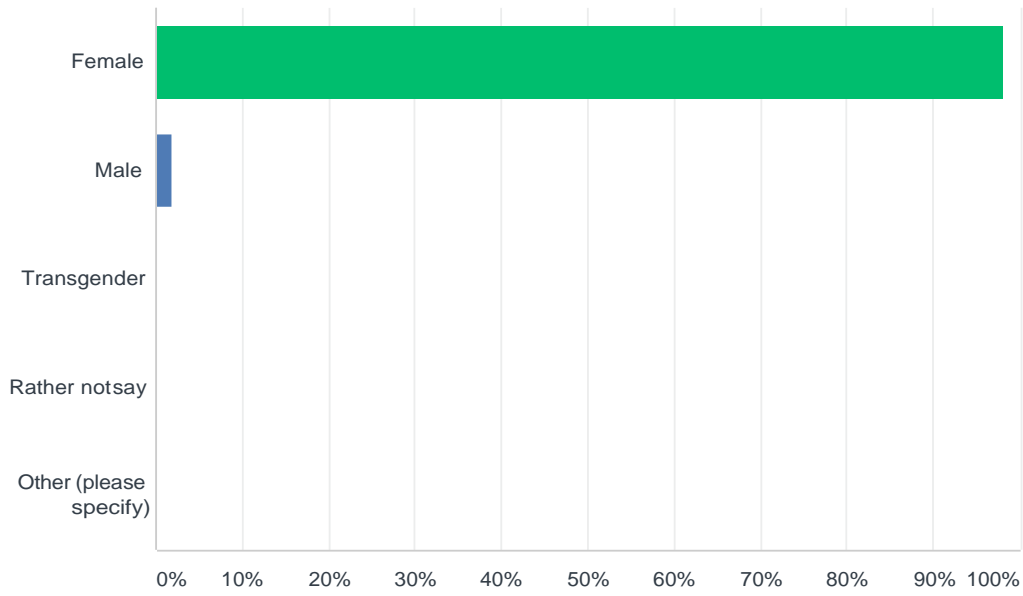
Answered: 53 Skipped: 8



ANSWER CHOICES	RESPONSES	
Yes	13.21%	7
No	84.91%	45
Rather not say	1.89%	1
TOTAL		53

Q16 Gender?

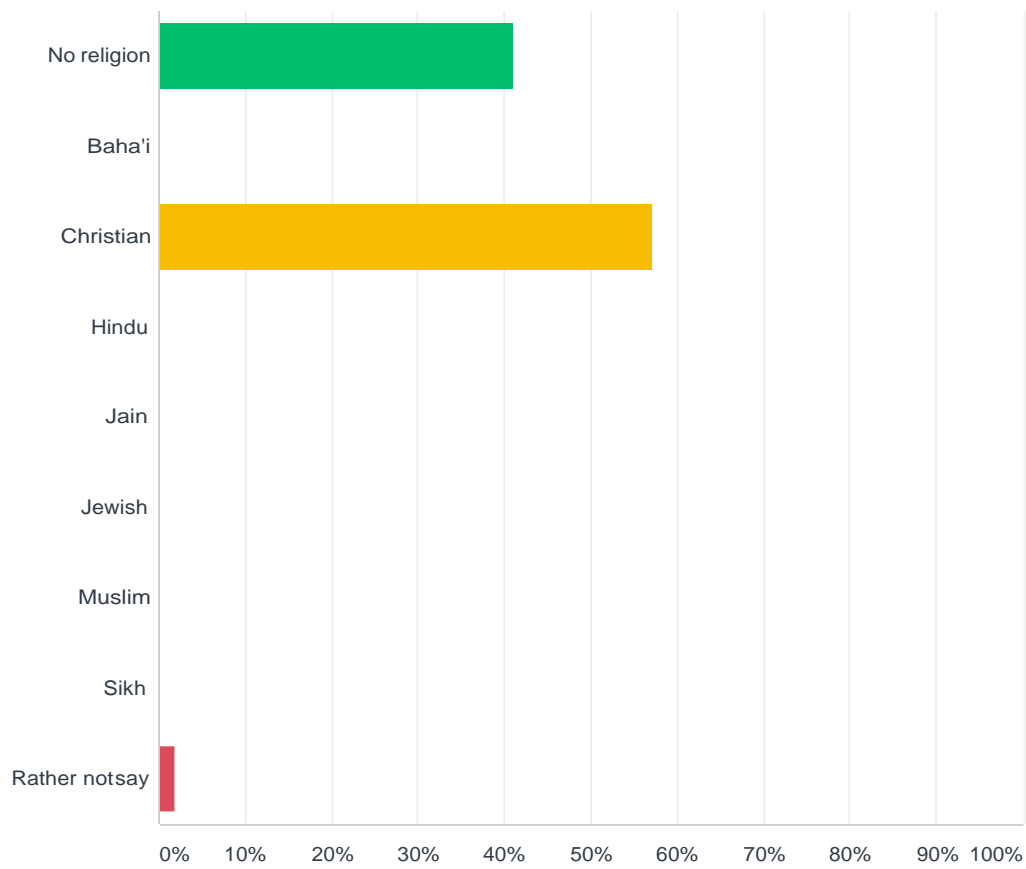
Answered: 56 Skipped: 5



ANSWER CHOICES	RESPONSES	
Female	98.21%	55
Male	1.79%	1
Transgender	0.00%	0
Rather not say	0.00%	0
Other (please specify)	0.00%	0
TOTAL		56

Q17 Which group below do you most identify with?

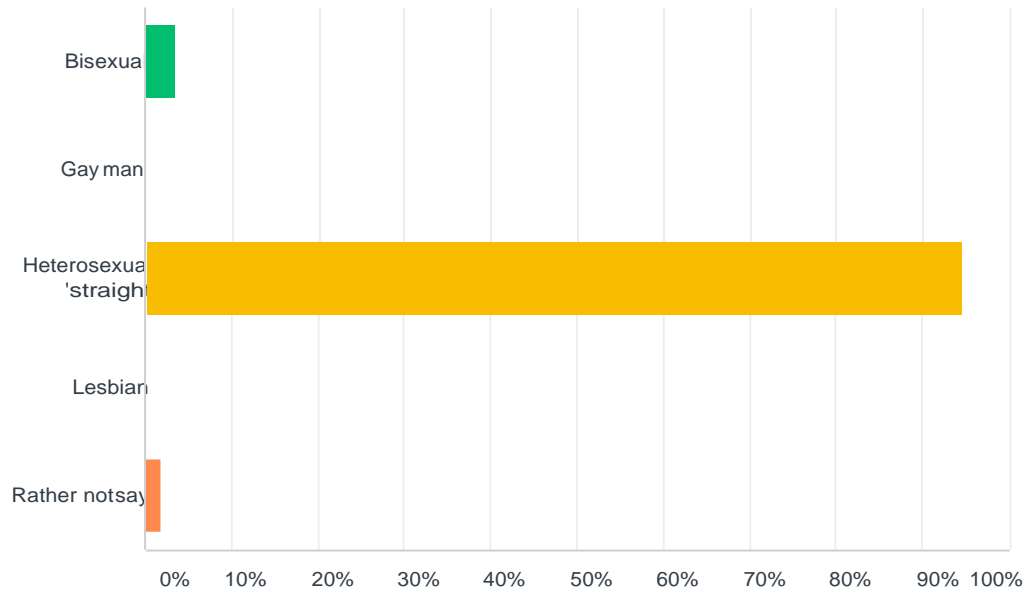
Answered: 56 Skipped: 5



ANSWER CHOICES	RESPONSES	
No religion	41.07%	23
Baha'i	0.00%	0
Christian	57.14%	32
Hindu	0.00%	0
Jain	0.00%	0
Jewish	0.00%	0
Muslim	0.00%	0
Sikh	0.00%	0
Rather not say	1.79%	1
TOTAL		56

Q18 How would you describe your sexual orientation?

Answered: 56 Skipped: 5



ANSWER CHOICES	RESPONSES	
Bisexual	3.57%	2
Gay man	0.00%	0
Heterosexual 'straight'	94.64%	53
Lesbian	0.00%	0
Rather not say	1.79%	1
TOTAL		56

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