



Teenagers and
Young
Adults with
Cancer



Bereavement support for young people experiencing the death of peers

TYAC Good Practice Guide for health professionals

Introduction

The aim of this Good Practice Guide is to raise awareness of the need to address and provide appropriate bereavement support to teenagers and young adults (TYA) experiencing the death of a friend to cancer through TYA cancer services.

Background

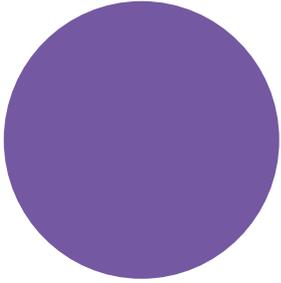
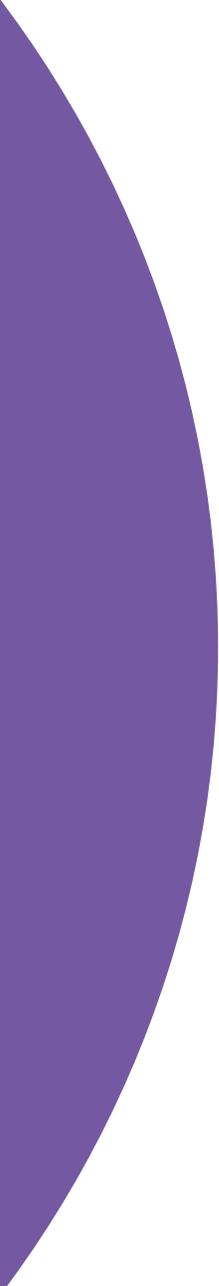
The ethos of TYA services is to encourage peer support to help TYAs cope with the physical and psychological impact of a cancer diagnosis. Due to the nature of the relationships that are built, and the shared experience that TYAs have, the death of young person within a cancer service can have a significant impact on other young people. There is very limited research into the impact the loss of a peer has on TYAs but some recent research tells us that they:

- Are more at risk of developing long term psychological difficulties if grief is not addressed at the time, i.e. risk of anxiety, depression or an increase in physical symptoms as a result of psychological distress [1].
- Require specialist support to develop coping strategies to deal with grief as they may not have the cognitive/emotional skills to cope with the bereavement (Child bereavement UK, 2018).
- May experience grief that is unique and complex to TYAs living with and beyond cancer as they may experience multiple bereavements. This makes them reflect on their own mortality; creates survivorship guilt, and a more intense level of grief due to their shared cancer experience [1].
- Often struggle to express their feelings about a friend's death and require encouragement to engage with this support.
- Should be screened for grief symptoms and offered bereavement support [1].

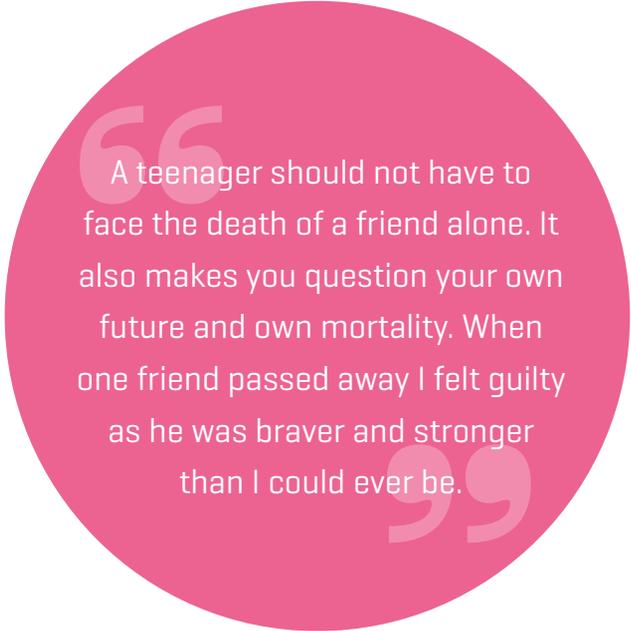
Young people themselves report that they would like bereavement support to be improved and they feel it is important that it is provided. Focus groups and online surveys with TYAs (The Christie, Manchester 'Remembering Friends project') have mirrored information found in research but also highlighted:

- They are fearful of making other friendships following the death of a friend, which can result in isolation from peer support.
- They have experienced difficulties with how a death is communicated by staff and often feel that death is a taboo subject on TYA units.
- They have felt guilty being at a young person's funeral and would like their own space to grieve too.
- They have their own views on what bereavement support is. They want bereavement support to be formalised, advertised and easily accessible across TYA units.

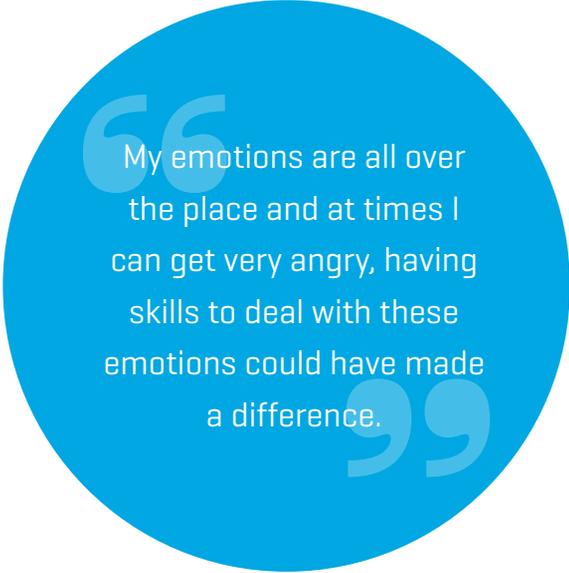
It is crucial that TYA services recognise the importance of addressing the bereavement support needs of young people and offer bereavement support in a way that young people want.



“ Sometimes it felt as though staff didn't know what to say and I felt guilty for asking about the person who had died.”



“ A teenager should not have to face the death of a friend alone. It also makes you question your own future and own mortality. When one friend passed away I felt guilty as he was braver and stronger than I could ever be.”



“ My emotions are all over the place and at times I can get very angry, having skills to deal with these emotions could have made a difference.”

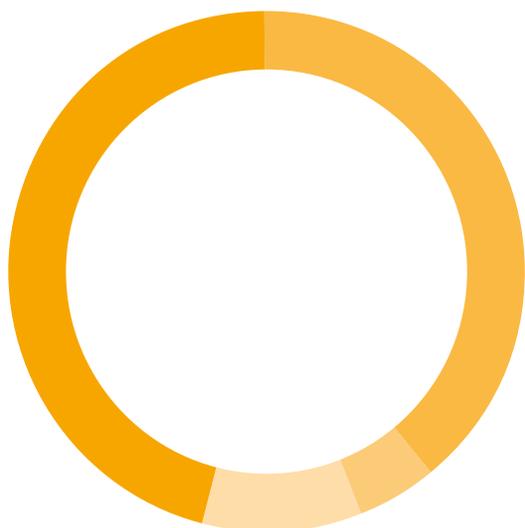


“ I had many friends who died and I still carry memories of them every day. I can just get a flash memory and cry.”

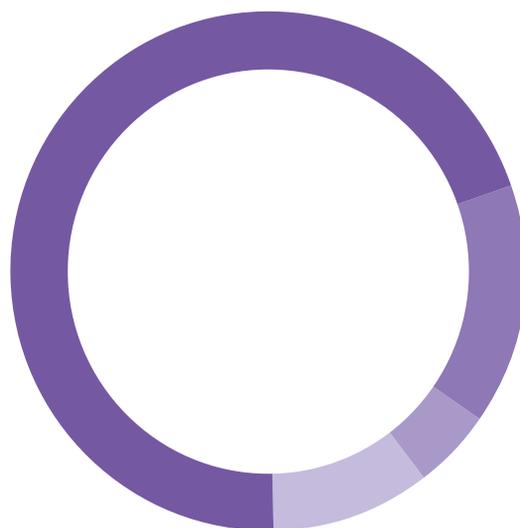
Synopsis of survey results

Nationally there is a lack of consistency in the bereavement support and services provided for young people following the death of a peer, with wide variations in practice. Despite these variations there is evidence of good practice throughout the country.

A survey was conducted amongst members of the TYAC professional body. 39 responses were received with representation from most regions across the UK. Respondents included:



Social workers/ community workers 46% ●
 Nursing 39% ●
 Youth support coordinators (YSCs) 5% ●
 Others (medical, management, admin, research) 10% ●



Principal Treatment Centre (PTC) 70% ●
 Designated hospital 15% ●
 University 5% ●
 Others (hospice, children's hospital) 10% ●

In the survey, 100% of respondents had no policy in place for supporting young people when they experience the death of a peer, although over 60% had plans to develop a policy in the future. The only barrier reported in doing so was time and resource [8%].

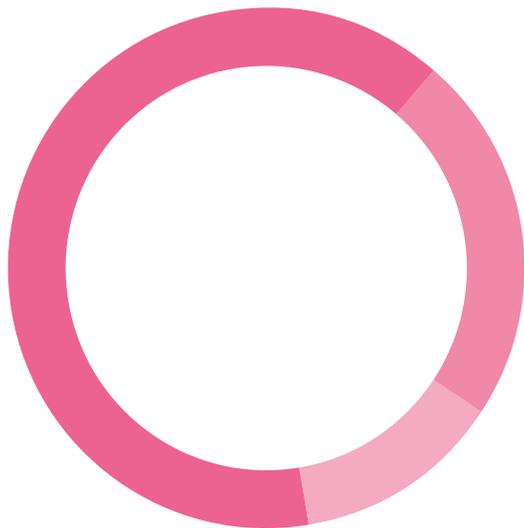
Current practice

Telling young people about the death of a peer:

There is general uncertainty among staff regarding what information can be disclosed to young people following the death of a peer. 28% of respondents said they would disclose the death to young people only with explicit permission from the family, whilst 18% would not disclose at all due to confidentiality and data protection. 18% would disclose the information only if asked directly, and another 18% felt it was appropriate to confirm the death with young people if they had already found out through social media.

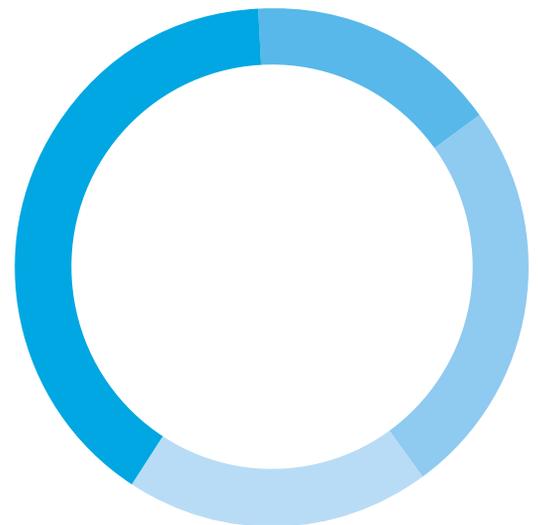
Bereavement support: What is available?

It is clear from the responses that a variety of bereavement support is available to young people and some services use several approaches. In the majority of responses [64%] a face-to-face approach was used, which included discussions with various staff [ward nurses, specialist TYA team, specialist bereavement workers]. A further 23% used a group approach which was facilitated by either a specialist TYA team or bereavement workers. 13% used dedicated bereavement services or facilitated events such as memory/remembrance days.



A face-to-face approach used 64% ●
 Used a group which facilitated by either a specialist TYA team or bereavement workers 23% ●
 Used dedicated bereavement services or facilitated events such as memory/remembrance days 13% ●

Signpost their bereaved young people to digital information/platforms for informational support 40% ●
 Quiet space for reflection within their unit/ward where information was available 16% ●
 Provided paper-based information 25% ●
 Use social media or signposted to bereavement websites 19% ●



Many respondents [40%] signpost their bereaved young people to digital information/platforms for informational support, whilst 16% had a quiet space for reflection within their unit/ward where information was available. 25% provided paper-based information which is freely available whilst the remaining 19% used social media or signposted to bereavement websites.

Bereavement events

64% of TYA services have a bereavement support event for young people. This takes the shape of some form of memory day/remembrance service where young people can share memories, say goodbye and celebrate the lives of their friends through a variety of reflective activities. These events are facilitated by various members of the multidisciplinary teams including YSC’s, CNS’s, social workers, AHP’s and clinical psychologists. Some events included chaplains and members of the palliative care team or hospital bereavement team.

What do we say as professionals when asked if a cancer peer has died?

How do we communicate the death of a young person to other young people?

It can be very difficult to determine what the best course of action is when asked by other patients or relatives, if one of the patients in your care has died. When formulating these guidelines, we sought advice from Clinical Governance Teams in the following NHS Trusts. Newcastle-upon-Tyne Hospitals NHS Foundation Trust advised that it is acceptable for staff to disclose the death of a cancer peer when asked by another patient in order to provide bereavement support. NHS Greater Glasgow and Clyde advised that if the patient is deceased, then data protection does not apply, however confidentiality is still applicable.

The advice of the TYAC Practice Development Group would be to discuss this with your local clinical governance team as different trusts may have local policies in place. We believe that best practice would be to confirm the death of the patient but not to divulge any details surrounding the circumstances of their death. Similarly, staff should only provide information on a patient's death when directly asked and should not initiate conversations even if requested in advance. For example, if a patient or relative asks: "Can you let me know when... dies?" It is essential to utilise your own clinical judgement when deciding if and when it is appropriate to share this information with another young person or their family.

If a patient asks if a cancer peer has died, they may already be emotionally prepared to receive that news and may already have an idea what the answer may be. This is often also a way of seeking confirmation to allow them to process the information and begin the grieving process.

Ask families if we can share the information

Where possible you should ask the patient's family if they agree to you sharing the information regarding the death of their family member with other patients and their relatives. Families are usually very aware that their loved one will have formed friendships on the TYA unit and will understand the importance of informing other young people.

Ask families if they are planning on sharing the information on social media

Similarly to asking the families if we can share the information, if you feel it is appropriate you can ask if they are planning on sharing this information on social media. Knowing if the information will be shared allows the TYA team to anticipate the support required for cancer peers on the unit.

Dissemination of news across wider teams

News of the death of a patient should be shared in MDT meetings and provision of bereavement support discussed in a multi-professional manner. This news can also be shared with other staff members who have been directly involved in the care of that patient. It is advisable to also consider staff members such as domestic staff and porters as they may have developed a close relationship with the deceased patient and their family.

Social media

Social media can be an incredibly beneficial tool for TYA teams - it can allow for dissemination of information to a wide group of people. Some teams use it as a forum for young people to share their thoughts and ideas about a wide range of topics relevant to themselves and their age group. It can be moderated by the TYA teams and therefore quite sensitive information can be discussed in a safe space. Each team should follow its own trust/health board's social media policy.

Social media also has its challenges. Families may share information about the death of a young person via social media, therefore young people in our services may be aware of a death before we are. This can be difficult if our hospital policy does not allow sharing of information.

The team who have produced this information feel very strongly that healthcare/TYA teams should not use social media to share information regarding the death of a young person whether that is directly or indirectly using symbols and emojis. It is considered good practice that to ask families whether they intend to share information on social media. This will allow teams to prepare for contact from young people who may be upset or may ask questions over the following days and weeks.



For further information and guidance, refer to the TYAC good practice guidance on social media use:
www.tyac.org.uk/tyac-good-practice-guides

Supportive services: What can we do? What should we do?

As a treating team working within TYA care it is important to recognise when and where your skill set and responsibilities start and end. Ongoing, in-depth bereavement support of young people is not usually recognised within TYA work/roles; we are not bereavement counsellors.

It is imperative that staff are mindful of the amount/quantity of bereavement support being offered to individuals. Professional boundaries must always be adhered to, and in-depth involvement with young people and families that is not equitable to others should be avoided.

It is important to recognise this limitation to roles and refer on as appropriate. This helps to maintain your status as a TYA worker and will protect you and the young person experiencing bereavement.

If you are a Principal Treatment Centre or Designated Hospital for TYAs we strongly recommend that you look to develop services to support bereaved young people and/or signpost to local or national services.

Low level, informal support may feel appropriate, referrals to psychological services may be necessary and referrals to bereavement counsellors may also help a young person in their grief.

Online or telephone bereavement support could be considered to be appropriate. A list of organisations providing a variety of support services is provided on page 11.

You may choose to develop bereavement services yourself within your own Trust. Where small scale/local projects are established it is imperative that services offered are equitable and consistent, e.g. holding a memorial event for every young person.

Services could involve [these are suggestions only]

- An annual remembrance event. This can be a celebration and be a young person friendly, informal event. The event should be developed with young people's involvement to ensure it meets young people's needs and is helpful. Models already exist across the country and can be disseminated where required.
- Open communication via a telephone line or email service that can be during working hours and can be picked up by members of the treating team.
- Making sure that young people know they can speak to members of staff about bereavement and the loss of friends.
- A place of reflection and remembrance within the TYA service. This could be a physical area or a book of remembrance.

Looking after ourselves as professionals/staff teams

In looking after ourselves and staff teams, it is extremely important to recognise the impact that the death of a young patient may have on our emotional well-being. It is likely that as a professional you will have spent a great deal of time with that young person and their family and it can be deeply saddening to learn of their death.

Clinical Supervision:

- Grief affects all of us in different ways but allowing the open discussion of feelings in a safe environment can have a positive impact on emotional well-being and minimise burn-out.
- It is also important to remember that professionals and staff teams are vulnerable due to the risk of cumulative deaths. Emotionally, this can take its toll especially if those staff members are attending several funerals in a short space of time. Most teenage and young adult units will have a local policy for staff attendance at funerals.
- If it is recognised that a few staff members require support, it is advisable to formulate small groups of professionals to discuss thoughts and feelings in a safe and confidential way. This element of support often proves beneficial and allows some time away from the clinical setting to explore our own coping strategies with grief and loss. Some colleagues may not wish to engage in this as they may not find it helpful but allowing them the opportunity for discussion on a one-to-one basis may prove beneficial.
- It is advisable to consider the wider team involved in the care of TYA patients, for example district nursing teams. They may not be looking after teenagers and young adults on a regular basis and may benefit from accessing support from their local TYA Principal Treatment Centre in the event of a young person's death.

Dissemination of the good practice guidance amongst our teams in hospital and beyond

Good practice guidance is only of benefit to healthcare professionals if it is grounded in theory and sound experience, but as important is that it is distributed across the widest possible audience. It is therefore suggested that this guidance is not only available on the TYAC website and advertised through the regular newsletters, but that it is distributed across the national teenage and young adult workforce.

The information contained within this guidance is likely to stimulate discussion and debate amongst teams and therefore face-to-face delivery is likely to be beneficial. This may be through team meetings at a ward level through to regional teenage and young adult meetings.

This guidance is designed as much for healthcare professionals based in designated and non-designated hospitals as it is for TYA teams in PTCs, particularly the sections related to sharing of information, what support is available and 'looking after ourselves as healthcare professionals'. In order to achieve dissemination across these hospitals this guidance should be shared through TYA network groups such as the TYA Pathway Board hosted by Greater Manchester Cancer.

The team that have produced this guidance do not see one particular individual as being key to sharing and disseminating, but that it needs to be a whole team approach so that all those that need to know, do know what to say and where to point people for the right support and advice.



Top tips

1. To have a policy that is disseminated across the whole team[s] on bereavement of young people. Speak to your local info governance team.
2. Consult with TYA as to what they require (and need) from a bereavement support service at a local level.
3. Provide opportunities for young people to talk about bereavement when other TYA die e.g. telephone number to call, quiet space on ward.
4. Provide or signpost to age appropriate information on the topic of death and loss of a friend.
5. Ensure the MDT is aware of the death of the young person in a timely manner and is then engaged in the supportive process for both young people and healthcare professionals. There may be a need to share information across hospitals if treatment is being provided at multiple sites.
6. If appropriate discuss with a bereaved family whether they give permission for the death to be shared with other TYA and families and whether they are going to share on social media.
7. Encourage self-care of all professionals working in the field e.g. staff support sessions, clinical supervision.

References

[1] **Johnson LM, Torres C, Sykes A, Gibson DV, Baker JN (2017)** The bereavement experience of adolescents and early young adults with cancer: Peer and parental loss due to death is associated with increased risk of adverse psychological outcomes. PLOS ONE 12(8): e0181024. <https://doi.org/10.1371/journal.pone.0181024>

Useful organisations for young people and for health professionals

Child Bereavement UK

www.childbereavementuk.org

Support children and young people up to the age of 25 who are facing bereavement, and anyone affected by the death of a child of any age. They also provide training to professionals in health and social care, education, and the voluntary and corporate sectors, equipping them to provide the best possible care to bereaved families.

Maggies (depending on local services)

www.maggies.org

Free practical and emotional support for anyone with cancer, and their family and friends.

Hope Again

www.hopeagain.org.uk

Hope Again is the Youth Website of Cruse Bereavement Support, with information, vlogs, podcasts, videos and sharing personal stories.

Winston's Wish

www.winstonswish.org.uk

Offering practical support and guidance to bereaved children, their families and professionals.

Grief Encounter

www.griefencounter.org.uk

Helping children through bereavement. Support services range from a supportive voice at the end of a phone, Grief Groups and Remembrance Days, to long-term one-to-one counselling.

YoungMinds Crisis Messenger

Provides free, 24/7 crisis support across the UK if you are experiencing a mental health crisis. If you need urgent help text YM to 85258 All texts are answered by trained volunteers, with support from experienced clinical supervisors. Texts are free from most networks.

Samaritans

www.samaritans.org

If you're in distress and need support, you can ring Samaritans for free at any time of the day or night. Freephone (UK and Republic of Ireland): 116 123 Email: jo@samaritans.org

Childline

www.childline.org.uk

Children and young people under 19 can confidentially call, email, or chat online about any problem big or small. Freephone 24h helpline: 0800 1111. Children and young people can sign up for a childline account on the website to be able to message a counsellor anytime without using their email address

Cruse Bereavement Support

www.cruse.org.uk

Charity providing bereavement support and information.



Teenagers and Young Adults with Cancer

Bereavement support for young people experiencing the death of peers: TYAC Good Practice Guide for Health Professionals

Authors: David Wright, Julie Cain, Laura Baker, Anna Mackland, Lorraine Wright and Nicola Holmes-Long on behalf of the TYAC Practice Development Group.

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Teenagers and Young Adults with Cancer [TYAC] is the UK's professional association for those who treat and care for teenagers and young adults with cancer. Our strength lies in our knowledge and understanding that teenagers and young adults have different and specific needs to children and older adults, and require age-appropriate care.

By providing information on good practice and new developments, training and support to our members, and through funding and supporting research into teenage and young adult cancer, we aim to improve the quality of life and likelihood of survival for young people with cancer.

Our purpose:

- To be the leading national platform for influence and progress in teenage and young adult cancer treatment and care.
- To support and empower our members through education, awareness, research and knowledge.
- To seamlessly bridge the gap between child and adult cancer care for all TYA patients.

We are working hard to break down barriers and fight for change for all teenagers and young adults with cancer.

Join TYAC as a professional member: www.tyac.org.uk/membership/become-a-member

TYAC's professional association work is supported by:



TYAC
Century House
24 De Montfort Street
Leicester
LE1 7GB

Tel: 0333 050 2589
info@tyac.org.uk
www.tyac.org.uk
f TYACancerOrg
t TYACancerPro
@ TYACancerOrg

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