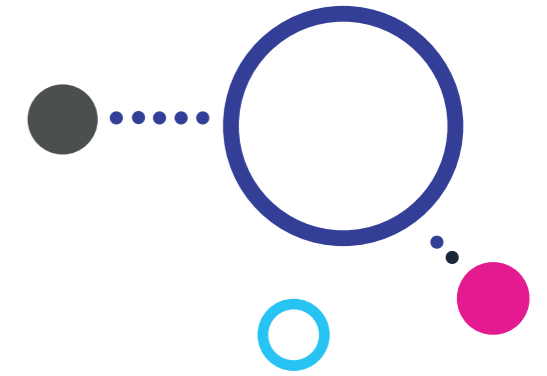


February 2019

# Insight Death Ting



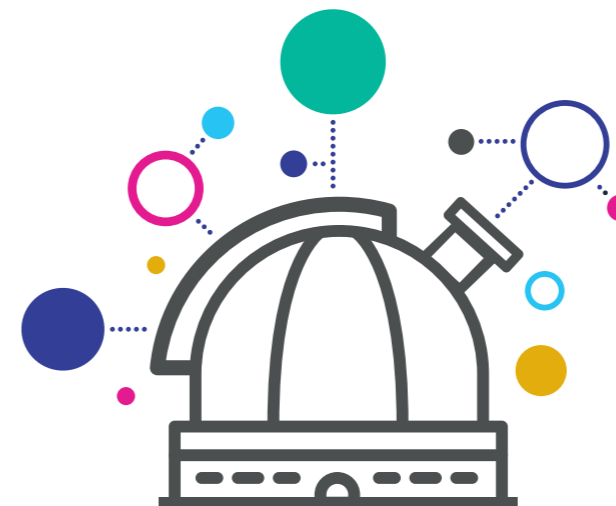
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## Executive Summary

Young Scot and the Scottish Government established a partnership to deliver a 'Ting' to identify the main issues of importance to young people around death and dying.

As a preparatory activity, Young Scot delivered an online task through the Young Scot Rewards platform to engage young people through writing a letter. The task received 325 completed responses, with participants ranging from 11 to 25 years old, from across Scotland.

### Clear themes included:

- » The death of family members and pets as key experiences of death, dying and bereavement.
- » Death and dying was perceived as something that comes to everyone, so is accepted
- » The fear of the unknown and the fear of what might happen to them or their loved ones.
- » Questions around what happens when you die, from theoretical and religious, to practical advice.
- » Support was identified in many forms, family and friends, as well as schools and teachers.
- » Avoiding the topic of death, avoiding the use of the word, talking about "passing away" or avoiding the subject.

To tackle such a sensitive topic with young people, Young Scot was required to work closely with partners and young people to ensure there was enough support in place before, during and following any delivery. As well as considering the capacity of the staff involved in the project, robust processes were put in place with the Scottish Government to ensure the needs of the young people involved were the key priority, including: an ethics review, a data protection impact assessment and ensuring informed consent was clear throughout. It was vital that the staff supporting each of the groups were able to support the young people participating. Information packs were disseminated to the young people to allow them to opt in to the project, as well as a consent form to ensure they were aware of the topic; delivery plan; and their right to opt out of being involved in the session or specific activities. Flexibility in the process was essential in allowing the young people to contribute however they felt able to in the moment.

Even with the support in place, the information and advice shared, this was still a difficult subject for young people to tackle. Following each of the workshop sessions the young people were directed to information and signposting to specific services available via the Young.Scot platform. Young Scot held five bespoke co-design workshops with 40 young people in total, between 15 and 25 years old. The four partners involved in the workshops were: a Clackmannanshire high school; LGBT Youth Group; Her Majesty's Young Offenders Institution Polmont; and Glasgow Disability Alliance.

### Key insights from the sessions included:

- » Parents and wider family were identified as the people they would primarily go to for support.
- » Friends were seen as both a positive support network and a potentially negative influence.
- » Partners and youth workers were also identified as positive role models or individuals they could confide in and go to for advice.
- » Professional support services were made use of as a source of impartial advice and an open space to explore their emotions.
- » Schools were primarily identified as support mechanisms when a situation affected an entire class or group of pupils, rather than support for individuals.
- » There was a lack of information, awareness and understanding for young people, from practicalities of the cost of a funeral to awareness of the support available.

Young people across all of the groups felt that talking about death and dying is positive, although it was clearly acknowledged that this can be incredibly difficult in different ways for each young person.

## Introduction

Young Scot and the Scottish Government established a partnership to deliver a 'Ting' to identify the main issues of importance to young people around death and dying. Through this broader conversation Young Scot looked to begin to develop understanding of the right support required for young people around bereavement.

This understanding provides insights that can be used by Scottish Government to influence and inform its decisions on improving young people's experience of death, dying and bereavement in Scotland. As an issue that impacts on all National Outcomes, the Scottish Government sought to begin a proactive conversation, with young people at the heart, to challenge our culture to make Scotland a better place to live, die and grieve.

### Background

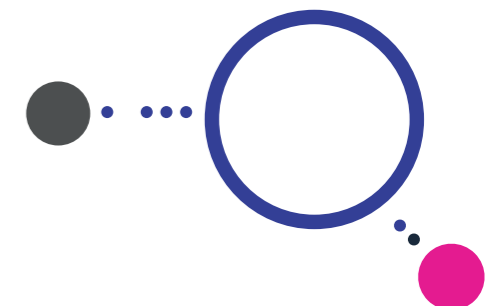
Ting is a Norse word for 'a gathering'. Across the Norse world people came together to make decisions on things that mattered to them. The word is still used today in the names of the parliaments of Iceland and Norway and survives in the names of Scottish places like Dingwall and Tingwall where Tings were held. Today it is being used for a process or an event where people from a range of backgrounds work together to explore and solve complex problems affecting them. A Ting can be a one-off or an on-going process, but it is always ideas and design-led and always provides a platform for people's voices to be heard equally to ensure a broad range of perspectives are considered. Tings are specifically designed to link people to power.

Young Scot delivered a series of workshops on behalf of the Scottish Government to examine young people's perceptions of and experiences of death, dying and bereavement, including how we talk about death with young people and how they can be supported through potentially traumatic events.

Supporting young people to co-design insights, ideas and solutions has been shown to have a radical influence upon service innovation, encouraging a more distributed, participatory and decentralised approach to support Scotland to work towards ceding power and responsibility directly to young people.

### Key aims

The key aims of this co-design initiative were to understand what young people see as the key, relevant experiences that have a lasting impact on their lives and decision making. By identifying possible ways to better support young people when they are facing or coming to terms with a bereavement, the Scottish Government can develop a better understanding on how to support young people through these experiences. To achieve this, Young Scot delivered a programme of youth engagement activity, working in collaboration with several core groups of young people and key partner organisations to gather insights and test attitudes towards the support they have received around death and dying, and to begin to develop appropriate ideas in which they'd like to receive support. This project has explored the use of Tings, along with the Young Scot co-design process, as a way of gathering the views of young people which can feed back into policy and actions. Through this combined approach, young people are able to develop insights around current experiences and support, begin to challenge current practice and develop support models tailored specifically to meet the needs of young people.





## “Dear Death...” Letters

As a preparatory activity to influence the development of the work directly with young people, Young Scot delivered an online task through the Young Scot Rewards platform to openly engage young people on the issue of death and dying through writing a letter. The task received 325 completed responses and with participants ranging from 11 to 25 years olds from Shetland to Dumfries, we have a snapshot into young people’s perceptions and experiences of death in Scotland.

There were clear themes throughout the responses, providing insights into the priorities of young people when talking about death, dying and bereavement.

- » A large majority of young people identified the death of family members and pets as key experiences of death, dying and bereavement in their lives. This varied from close family members in traumatic and life changing experiences to distant relations when they saw the impact of the bereavement on other people.
- » Death and dying was perceived as something that comes to everyone, that is inevitable, so was accepted by many of the young people as a part of life. This was mixed with both positive and negative feelings, as well as a wide variety of lived experiences.
- » A fear of death was clearly identified by many of the young people who participated, both in the fear of the unknown, and the fear of what might happen to them or their loved ones. This was expressed by those who shared their own experiences of death, dying and bereavement and by those who could not clearly identify a time they felt it had affected them.
- » There were many questions posed around death and dying, around what happens when you die and covering a wide variety of topics from theoretical and religious queries, to practical advice for those dealing with the experiences.

- » Support was identified in many forms, family and friends, as well as schools and teachers. Most of the young people who identified family and friends as support mechanisms did so in a positive way, appreciating the help they received to deal with any difficult experiences. Those who identified school as a support varied from positive support from teachers specifically, to a lack of any support or advice when dealing with their own personal experiences.
- » Avoiding the topic of death was clearly identified throughout, whether that was avoiding the use of the word “death” and talking about “passing away” or avoiding the subject entirely. Several of the young people wished for more discussions throughout their lives around death and dying, while others identified how difficult it can be to talk about.

The clear priorities emerging throughout the ‘Dear Death’ activity provided the basis for the work directly with young people, with a clear focus on the experiences of death, dying and bereavement; the variety of forms of support young people have when dealing with these experiences; and how young people talk and think about death and dying more generally. These themes were explored throughout the programme of activity delivered with groups of young people. The openness of young people in sharing their experiences and feelings reiterated the need to ensure that a robust process was in place for engaging with a variety of groups.

## What We Did

### Young Scot and the Scottish Government

Before beginning the delivery of the programme of activity, to ensure the staff within Young Scot had the capacity and confidence required to deliver the programme an information and awareness training session was delivered with support from the Children’s Hospice Association Scotland. This equipped all staff with the necessary skills and awareness to both develop and deliver the programme in a way that was sensitive to the needs of the young people participating and those supporting young people to engage in this way.

As well as considering the capacity of the staff involved in the project, robust processes were put in place with the Scottish Government to ensure the needs of the young people involved were the key priority. This included completing an ethics review, a data protection impact assessment and ensuring informed consent was clear throughout.

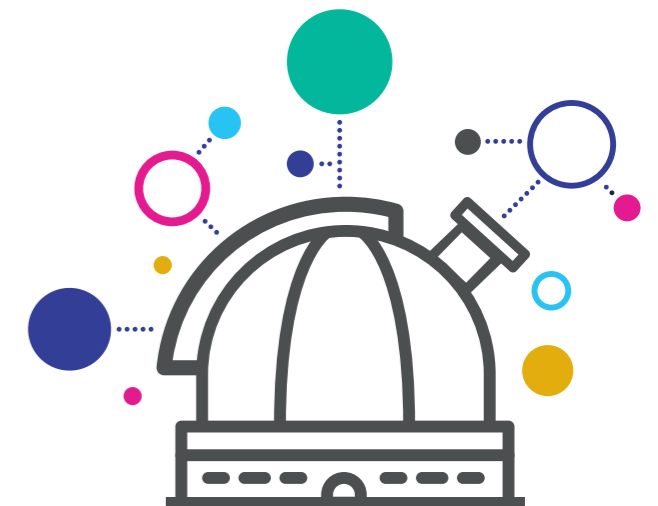
### Those Supporting Young People

Four groups were recruited using Young Scot’s national partners as well as sharing this opportunity with our Local Authority partners through Young Scot Localities Managers. This opportunity was open to all of our local and national partners working with young people, although specific groups were asked to be involved in the project to ensure a wide range of experiences were shared.

A clear outline of the commitment involved in being part of the project and the scope of the programme was shared with each of the key contacts for the groups, with the opportunity to discuss further if interested. This allowed those working with young people, who had built up strong relationships, to consider if this was something they felt appropriate to offer out. Some partners felt that the short-term nature of the project was not appropriate for their young people, having been previously involved in similar pieces of work out with Young Scot. This is something to be considered in the future when delivering the Ting model. It was also key that the staff supporting each of the groups were comfortable being present during the workshop sessions to support the young people who were participating, which understandably proved challenging for some partners.

Although there was a definite appetite from local partners to get involved in the project seeing the engagement on the topic as a valuable opportunity, this came with some hesitance to ensure that the young people they work with were as supported as possible throughout and that the insights gathered were going to make a lasting impact on young people in Scotland. This therefore required a commitment not only from the young people to participate but also for the staff supporting them, to ensure the young people were continuously supported throughout the programme and following it.

Working with pre-established groups made this more feasible, with strong relationships already formed. The nervousness from those that work directly with young people in both schools and youth groups provided an additional challenge when recruiting groups to get involved. Although we were able to confirm the interest of groups, with dates in the diary, these were cancelled on multiple occasions last minute due to the challenges perceived in addressing this topic by the “gatekeepers” rather than a lack of appetite from young people. This meant that direct engagement with young people in the project was heavily delayed and required careful consideration in order to reassure the staff supporting them.



### Delivery

From this recruitment Young Scot held five bespoke co-design workshops with quality, in-depth engagement with 40 young people in total. Each session had between three and 15 young people from across Scotland, including Glasgow, Polmont, Clackmannanshire and South Lanarkshire, from four different partner organisations, who contributed 75 volunteer hours in total. The young people that attended the workshops were aged between 15 and 25 years old from a range of different backgrounds and with a variety of experiences.

The four partners involved in the workshops were as follows:

#### » A Clackmannanshire High School

A six-year comprehensive school Clackmannanshire. 15 young people in fifth year, all aged 16 years old and from the Clackmannanshire local authority area, participated in the Death Ting project.

#### » LGBT Youth Group

Through youth work services in Greater Glasgow, young people can be part of youth groups specific to their interests or needs, including an LGBT group who meet on a weekly basis from the local area. Three young people participated in the Death Ting workshops.

#### » Her Majesty's Young Offenders Institution Polmont

HMYOI Polmont is Scotland's national holding facility for male young offenders aged between 16 - 21 years of age. Sentences range from six months to life. Two groups participated in Death Ting workshops with five protected young people and eight mainstream young people.

#### » Glasgow Disability Alliance

Glasgow Disability Alliance (GDA) is a membership organisation run by and for disabled people, with over 4000 members across Greater Glasgow, who deliver free and accessible learning and events. Nine young people with a wide variety of experiences and support needs participated in a Death Ting workshop.

Young Scot initially intended to involve between 12 and 15 young people in each session but following the first workshop, using an iterative process, this was scaled down to be no more than ten. This allowed the conversations with the young people to be more in-depth and focused. Although, Young Scot prepared a clear session plan to deliver activities with each of the groups, this was adapted throughout the process to tailor to the needs of the young people, including literacy and numeracy, and the environment. This also encompassed how the data and insights were collected, ranging from designed tools, written notes, scribed sessions, as well as audio recordings. Each group was involved in a workshop session, bringing together young people to gather insights, with the key themes identified through the 'Dear Death' letter activity acting as a basis.

These were:

- » Their perceptions and experiences of death, dying and bereavement.
- » Any support they had received to deal with these experiences.
- » How they would like to talk about the topic sensitively and appropriately.

Using the Young Scot co-design process, the topic of death, dying and bereavement was explored broadly through the use of 'Death Café' style questions, allowing young people to broach the subject in a more relaxed fashion. This provided the space for the young people participating to share as much or as little as they felt they wanted to, while others chose to opt out of the discussions if they did not feel comfortable contributing at that point.

In order to explore the experiences and perceptions of the young people involved, they were asked to consider their own experiences of death, dying and bereavement on any scale. This provided the opportunity for them to look back at who may have discussed the topic with them and how this was discussed, as well as the experiences themselves. This activity took place in a variety of ways depending on the group, from sharing stories to writing out examples and depicting a full timeline of experiences across the group.



By reflecting on the support, advice and information they had been given throughout their lives around death and dying, the young people were able to identify and develop the potential solutions that would support them through these experiences.

Flexibility in the process was essential in allowing the young people to contribute however they felt able to in the moment. By adapting each of the activities, Young Scot was able to support the young people to be part of this conversation more fully, depending on their individual needs. Even with the support in place, the information and advice shared, this was still a difficult subject for young people to tackle. Several of the young people did not feel comfortable in discussing the topic and did opt to either not contribute or to leave the session.

Following each of the workshop sessions the young people were directed to information and signposting to specific services available via the Young.Scot platform. This ensured that they not only had access to direct support in the key contact for each group and the lead from Young Scot, but they could also access information and advice at any point following the session.

One of the groups specifically reinforced the support available to their young people as they felt it was required following the initial conversations. This came in the form of a creative session immediately after the workshop exploring any of the feelings that may have been brought to the surface throughout activities and discussions. By allowing the space for the young people to continue the exploration of the topic they were able to build further resilience in the process.

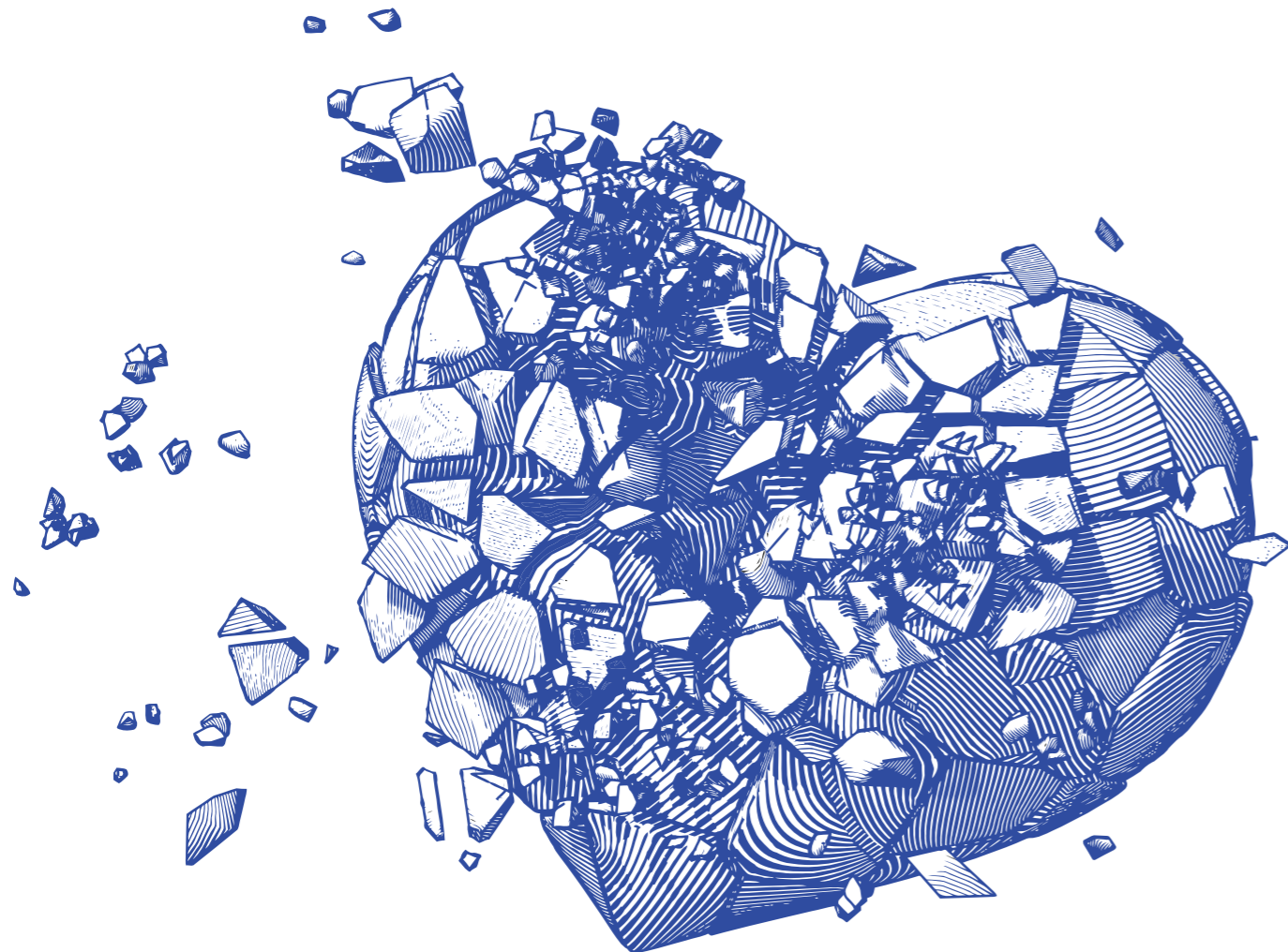
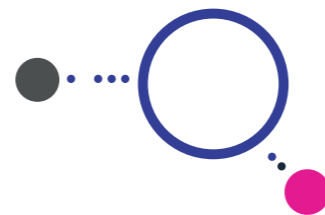


## Priorities for Young People

There were many issues and ideas discussed by the groups during the workshop sessions and there were clear themes identified. The participants felt that it is important that when supporting young people around death, dying and bereavement, the following should be considered:

- » The support provided to each young person must be specific to their needs, circumstances and attitudes.
- » Young people feel that talking about death and dying is positive but acknowledge that this can be incredibly difficult in different ways for each young person.
- » Young people need more information and awareness of the support available to them when dealing with these experiences.

By focusing and addressing these areas, young people in Scotland experiencing death, dying and bereavement will start to feel more supported throughout. However, the group realises that this is the first of many steps needed to begin a conversation around this sensitive topic.



## Exploring the Topic

The group explored the topic and what it means to them through a variety of activities and conversations. This included their own experiences, the experiences of friends, family, or that of their peers, as well as their perceptions of other young people in Scotland.

### 'Death Café' style questions

To start conversations around the topic, some 'Death Café' style questions were explored, with each participant answering the question if they felt comfortable to do so and putting their answers to the rest of the room. This allowed us to ease into the conversations around death and dying, in a more light-hearted way, giving the space for the young people to share as much or as little as they liked.

### The questions included:

- » What is on your 'bucket list'?
- » What song do you think represents you or would you have played at your funeral?
- » How do you think people would remember you?
- » What does it mean to you to leave a legacy?
- » What would you choose for your last meal?
- » You're hosting a 'death dinner party', who would you invite?
- » What do you think would be written on your tombstone?

### What is on your 'bucket list'?

When thinking about what they'd like to accomplish in their lives, the answers across the four groups varied from achievements, to wild and creative dreams.

Some young people had aspirations for their careers, including ambitions for the relatively near future, such as saying "I'd love to be thought of as the best director, but I don't need that. To at least make a film". Others focused on their personal ambitions: one participant noted "A few years ago, we said we were going to do a climb for the SSPCA, and we've never done it yet, but like Ben Nevis or something"; others looked broadly at concepts such as getting married; buying a house; moving abroad and having children. Most of the participants listed a few wilder ideas such as: swimming with sharks; flying in a private jet; parachuting; and bungee jumping.

A few of the participants from HMYOI Polmont also mentioned ideas that they were not able to do currently due to their environment: "being able to do day to day activities"; "stay out of jail"; and "visit Butlins – it brings back good memories!"

### What song do you think represents you or that you might have at your funeral?

The young people either chose to identify the song that most represented them or a song that they'd like to have played at their funeral, that people would remember them by. Most of the participants chose songs that were meaningful to their families, such as "Donald Where's Your Troosers - That was when papa's casket was going down the hole and that song started to go on and we just started to laugh. My papa used to sing it and that's the song that represents me because I've heard it so many times". Another participant linked this question to their own values, referring to "Not Afraid by Eminem. Every word in his songs I can relate to. That song is my inspiration because I'm never afraid to take any kind of stand and make every effort that's possible".

Other participants shared stories that reminded them of specific experiences, such as something quite traumatic: "Mama by the Spice Girls. When I was seven I was diagnosed with a brain tumour and when I was going in for my operation I was given less than a 1% chance to survive it. My big sister sang it but instead of singing mama she would say my name". Conversely, participants also drew from positive, happy memories, such as "the song I won my cubs talent show with – She Bangs by Ricky Martin. I was in the newspapers and everything!".

In specific reference to songs played at a funeral, some participants chose songs that they would like others to remember them by, including "I'd quite like Pink Floyd, Wish You Were Here. I don't know why. I like that song but it's quite sad. If that was someone's lasting memory of me, I'd like that to be it". Most agreed that they "would want people to feel sad but happy at the same time", that was "fun and that celebrated their lives".

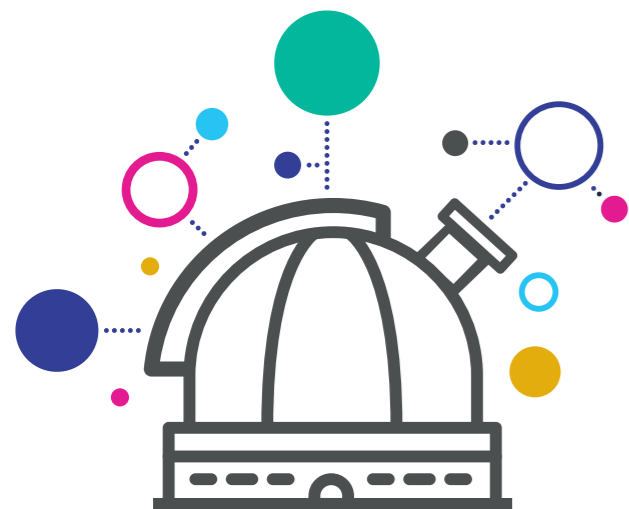
**How do you think people would remember you?**

The answers shared by participants varied from group to group. The youth group based in Greater Glasgow and the group from the high school in Clackmannanshire identified character traits and lasting impressions they hope to have on the people around them: “me personally I think I’m a bubbly, outgoing sort of person so I think that’s how people would remember me”; “with people close to me I hope that they remember me for whatever role I’ve playing in their life. My boyfriend, if he’s here after me, I want him to remember the good times that we had and the importance we are playing in each other’s lives”.

On the other hand, the participants in HMYOI Polmont identified an overall view that they hoped they would be known by. One group member said that they “would like to be remembered as a good guy and for the good things I’ve have done”, clearly identifying that how people view them could be very different person to person and what others’ perceptions are of them.

The young people from GDA specifically thought about how they are viewed by other people, and the impression they hope to leave on those close to them, noting that “I would say my determination and my strength that I have to try and make life better. To stop having strangers treating me like a child because they think ‘she has a disability, but her parents aren’t treating her like a kid’. That’s what I think I would be remembered for and just enjoying my life every single day. That’s what I want to pass on to my family and when I have kids I’d want them to live every day to the fullest”.

This was something they had contemplated more fully within the context of their own families: “I think it was yesterday my nephew actually knew, he’s only 6 and he said if anything happens to you, you’re the person that runs down everybody in their chair. I’m a man now and I need to just live my life the way I want to go about it and I don’t let any disability of mine run me down”.



**What does it mean to you to leave a legacy?**

Leading on from the previous questions, participants identified not only how they would like to be remembered, “to be known as a loving husband and good dad” and having a positive reputation, but also the impact they might have on the world around them. One participant explained their perspective, saying: “I suppose your legacy is about leaving the world in some way better than when you came into it. To make an impact to someone, literally anyone in the world. I would love it to be people I’m close to, but even if a film I’ve made meant something really special to someone, like the film they put on when everything’s going downhill in life and they wanted to watch this film that made them happy, that would be perfect. I’d like someone somewhere to remember my work when I’m gone, because that’s something important to me and that’s what I want to do with my life”.

The impact the young people can have on their families was of highest priority, even to those who cared little about leaving a legacy. An example of this was the comment that “My goal’s always been to try and bring my family together. When I leave the world, I think I’d want family to know what true family means. I think that means holding together”.

**What would you choose for your last meal?**

Most of the participants discussed their favourite foods and indulging in luxury, but conversations turned quickly to meals that meant something to them or reminded them or a positive memory in their lives: “I say it would be my mum’s spaghetti Bolognese. When I was 6 months old my parents used to give us spaghetti Bolognese and my mum and dad made jokes that they had to have a bath ready to put me in because I was covered”.

Homemade meals were the most common answers, because of the positive feelings it created for them. One participant talked about “one of my mum’s good homecooked meals. That homely feeling”.

“My goal’s always been to try and bring my family together. When I leave the world, I think I’d want family to know what true family means. I think that means holding together”.

**You’re hosting a ‘death dinner party’, who would you invite?**

When discussing who they might invite to their ‘death dinner party’ answers fell into two categories: their families and people they know; and celebrities or famous people from history they would like to meet.

Most of the participants chose grandparents who died when they were younger, in order to spend more time with them that they maybe did not have previously. One participant talked about: “My uncle Stephen, he got taken away from us at a young age. He was 20. My grandad, who was like my best friend. My two great-grandparents”; and to catch up on lost time, “my gran, to tell her what’s been going on”. This included family members that they knew well and not necessarily those just from previous generations: “I would like to see my mother’s father, because my dad’s parents never really had an impact on my life. They were quite old when I was quite young, so they were kind of out of the picture. My dad didn’t really talk about them, so I don’t know much about them. I know lots about my mum’s family and her dad, even her grandmother, they seemed like really interesting people that I’d want to meet. I’d want to meet her grandmother and I’d like to see my papa”.

The two groups from HMYOI Polmont all agreed that they wouldn’t want to invite family members as they felt that it would be too hard to say goodbye again, so instead chose celebrities or figures in history to find out more about their lives: “2Pac, Biggie Smalls, Hendrix and explorers, to find out where they have hidden treasure!”. This was particularly prominent in these groups, having very little time with their families on a day to day basis.

The majority of the participants also chose at least one celebrity that they aspired to meet such as a famous film director and actor, or someone that meant something to them specifically. One example of this was: “Whitney Houston. I just love her. For that one night at my wee death dinner party, I’d just have her sing one of her songs”.

**What do you think would be written on your tombstone?**

Participants continued the discussion by talking about how they would like to be remembered on their tombstone, with one young person saying: “I think I’ll have something like the guy that always made people laugh, because that’s how I am, I make people laugh”. Others referred to something that more broadly represented their lives and interests, mentioning “a quote from someone, or a lyric from a song. Something that means something to me. Something that seems a bit profound. I also like the idea, that if I wasn’t buried, like a monument or a big interest rock, planted in the ground. A memorial to me”.

This also brought up the conversation about whether they would like to be buried or cremated. Some of the young people involved had thought about this already, particularly in the GDA group: “I’ve already decided since I was 15 that I’ve always wanted to be cremated because I want my ashes to be buried where my holiday home is, that’s my favourite place in the world”, but this was new to most participants. Opinions varied depending on their families and experiences of other people’s decisions, being able to visit a gravesite or scattering someone’s ashes.





## Experiences of Death, Dying and Bereavement

The group were then asked to think back to their first memory of death, dying or bereavement, how this made them feel and who spoke to them about it. The young people who participated in the workshops openly shared a variety of experiences, ranging from experiencing the loss of pets and grandparents, through to traumatic losses of those close to them.

Family pets played a large part of the initial conversations within each of the groups, from a very young age, through to much more recently. Most did not understand the loss at a young age, noting that “My parents told me that because of his old age my dog had passed away. I was young so didn’t really understand what was happening but felt lost for a while without him being at home”. This had an effect on the family and could still be traumatic for them as children.

Other participants shared how their parents tried to soften the news and support them through the loss: “My hamster when I was four or five. I was quite sad at the time, my mum sort of explained a bit, saying he’d gone on to heaven, he’s with his family and friends now. I asked, ‘what is heaven’ and my mum explain that it’s where we go after we’re here. She made it sound more fun, like there’s an ice cream van that goes around all the time. We buried him in the black bin, but we put him in a shoe box with holes in it, with food and sawdust, just in case. Mum was there to support me through it”.

Many of the first experiences of death, dying and bereavement that the participants identified and shared were around the loss of grandparents. One of the young people spoke about his first memory of death being when his gran died when he was around the age of seven or eight. He remembers his brother explaining what had happened but not really understanding. He felt like there could have been some support from an earlier age to help him understand what had happened, as it was not something that was discussed even in school, although many of his peers experienced the same things at that age. This was demonstrated throughout the stories shared, of the loss of grandparents but the lack of understanding: “I didn’t really know what to think but found it upsetting watching someone I loved going through the pain they were in”. Although many of the participants were younger when their grandparents passed away for some this was more recent and difficult to deal with emotionally, with one young person sharing: “My grandpa passed away in 2014. He was my step grandpa and was in my gran’s life for 10 years. He was an amazing guy. When he passed on I just couldn’t function. I dragged myself to death. I didn’t enjoy my birthdays or life”.

One of the participants shared a similar story of loss of grandparents, but felt they had a better understanding of what that meant due to attending church at a young age and having this discussed throughout Sunday school. This was echoed further by another participant who felt that their experience of religion and the part that played in their life meant they were more equipped to deal with the loss: “I did understand about my grandfather dying when I was 16. They said remember the way that they were, don’t remember the negative things and don’t be upset, don’t dwell on it. Remember the life, it’s what happens to everyone. We still talk about it. The way I think about death, is that God has a plan for everyone, obviously God decided that it was his time to leave earth. That’s the way I’ve been brought up, that God has a certain timeframe for you to live, when you’re going to be alive, being born and God decides if it’s over for you. My mum and dad are Christian and have that upbringing, that God has everything planned for you”. Although the two participants openly talked about the part religion played in their lives, this isn’t something that was discussed by the participants more broadly.

Many of the participants shared feeling upset, not necessarily by the news itself, but by seeing those close to them upset. A participant shared that he remembered coming home from school and his mum letting him know that his gran had died. He could see the sadness that people were conveying but due to his age his mum never went into any great detail about what had happened. Another member of the groups shared that a close family friend died in an accident when he was eight. His dad explained what had happened, but he remembers feeling upset because his dad was upset, and it was the first time he had seen his dad react in that way. Sharing in the grief of those close to them, even when they did not understand what that meant in reality was demonstrated throughout all of the groups, in a variety of different situations around death and dying.

Similarly, the death of celebrities and influential figures was mentioned to have an effect on some of the participants, but more broadly because they understood the impact they had on their lives and interests. An example of this included: “They maybe weren’t important to me at that time but as I’ve got older, people like David Bowie and Prince, they’ve become more important to me over the years”.

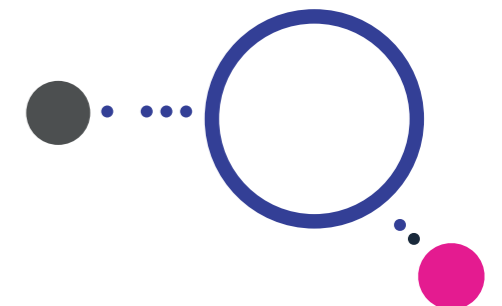
While many of these experiences were difficult for the young people to go through, others shared experiences that they had around death and dying that affected their behaviours and how they viewed their own lives. One of the participants shared that his girlfriend had a miscarriage. He said that this had massively affected him, although he had begun to change his life around now, he ended up going “off the rails drinking, taking drugs and getting in trouble with the police”. He said he did not realise at the time, but he “had broken down and didn’t care what happened to him”.

Traumatic experiences, even when they had taken place at a young age, were still thought of regularly by some of the young people. One participant recounted that “I was nine and a boy that I knew got killed right in front of me. He thought it was funny to do a dare with his friends, and I was around when he was doing it, but I had a fear of bikes so didn’t join in. He got hit by a truck because he had no breaks on his bike and he went right in front of it. Every year I think about him and where he could have been”. This example shows experiences having a lasting effect on how young people view their own lives.

Specifically, the participants from HMYOI Polmont shared how although experiences of death, dying and bereavement could be difficult for them to get through, this was made much more difficult when they were unable to be with their families and friends, supporting them through those situations. This is exemplified by one comment from a participant, who said that “My girlfriend’s grandad passed away while I was in here. I feel sad about them but more so for the ones that have happened while I’ve been here, feel upset and disappointed in that I wasn’t there for those people”. This was echoed by other participants throughout the two sessions delivered in HMYOI Polmont.

Several of the participants had experienced the loss of a parent, both at very young ages when they did not fully understand and when they were slightly older: “When I was 13, my stepdad died of a brain tumour. My dad decided to leave when I was younger, my stepdad came in to three children, which someone wouldn’t normally do. But he was the best dad ever. Still can’t believe he’s gone”. While most looked to family and friends for support in these difficult situations, others also looked to outside support with one of the participants specifically directed to a counsellor by another family member.

One of the participants shared that the loss of a parent is something that he is going to have to deal with in the near future later due to the ill-health of his father: “Realistically speaking my dad’s not going to be about by the time I reach 25. He’s got dementia and Parkinson’s disease so he’s in a care home at the moment. He’s doing ok at the moment actually. He’s 65 this year. He got it really young. But the stage of Parkinson’s that he’s at, the doctor said he’ll be really surprised if he’s still here. He’s on a lot of medication so it’s under control. I go to the home to visit. He’s deteriorating and every 6 months we see a big deterioration. I’m 18 so by the time I get to 25 he’s probably not going to be here”.







## Influences

Thinking about both their experiences of death, dying and bereavement, and more broadly, the young people were asked to consider who they felt might have an influence on their own decision making, both positively and negatively.

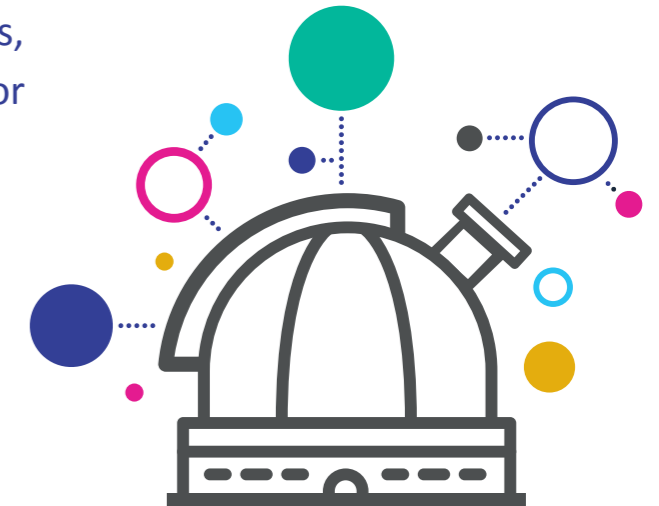


The majority of participants identified parents as positive role models in their lives that they would trust for advice and support through any situation. Participants mostly aspired to be like their parents, specifically in difficult situations. Parents were seen to be a constant in their lives that they could rely on, although this varied depending on the type of relationship they had throughout their lives. One participant noted: “my mum, just because I’ve had no dad for my full life. My grandad was some kind of positive but he’s kind of absent as well. So just my mum, my rock”. It was also identified that the participants felt family would not judge them for what they had done or how they were feeling but supported them through any situation, sharing their emotions and bereavement.

Participants spoke positively about how they were supported by family, even when family members might also be going through difficult experiences themselves, and the admiration they had for them for this strength and support. One participant recalled that “When my papa

died, I was there for her and she was there for me. It really hit her hard but she’s very strong and she got through it. She didn’t have any depression or anything like that. I remember at his funeral she got up and did his eulogy, and she’s the quiet one out of her family but she wanted to do it. So, she got up in front of everyone and did it, because it was her dad”. Across the group sessions, partners and youth workers were also identified as positive role models or individuals they could confide in and go to for advice. Television, celebrities and acquaintances were all identified as less positive role models that may not demonstrate positive life decisions or provide support in times of need. Several of the participants also put themselves in this category, highlighting that they may not always make the right decisions for themselves and those around them. This was particularly prominent in the groups at HMYOI Polmont. Although not necessarily a “bad influence”, work colleagues were categorised as negative influencers as they felt they are more focused on the job than what you may be going through in your personal life.

Participants spoke positively about how they were supported by family, even when family members might also be going through difficult experiences themselves, and the admiration they had for them for this strength and support.



Friends were seen to be both positive and negative influencers, depending on the group and the individual. The groups in HMYOI Polmont felt that friends were more likely to be negative influencers as they would often be led astray by them and felt that they may not fully understand what they were going through. Several participants identified that it might be difficult for others to support them through traumatic life events as well, including noting that “We had arguments like that when we were growing up. When I first lost my uncle, we did have a few falling outs. She didn’t know how to comfort me, and I did lash out because I was hurting. It tore our friendship to the limit. We got through it. They might just not have the words. You just have to listen”.

The participants across all the groups identified schools as possible influencers in their lives and areas for potential support, however very few participants said they would look to the school when they are experiencing death, dying and bereavement. Some of the participants shared stories of how their primary schools supported them in difficult situations, including: “To support each other in school, some of us decided to start a ‘Jack Murray’ Award, so for

my friend that died. I would speak to my friends in school but it’s hard because it will upset them, and we were trying to forget about it. Want to talk about it but it’s hard to talk about it when other people are going through it as well”. In addition, a couple of participants identified specific teachers that they would look up to and trust for advice. A few of the participants identified other influences that may help them through their experiences of death and dying, such as: “famous rock stars, and listening to a song that means something to you, but that could be to do with any kind of passing of someone, if you listen to a song it can cheer you up, it can make you think of something better, it can make you think of that person, and can make you think of good things about them. A song or a film or anything”. The love and attention of pets or adopting new animals after the passing of their previous pets was also mentioned by participants: “we did support each other as a family and managed to heal eventually and then we did think about getting another dog, to give that wee puppy the same love that we gave her, we could help her spirit come back”.

## Talking about death

Each of the groups of young people were asked to think about going through the experiences of death, dying and bereavement, or just when thinking about the topic area, who is there to support them and what they might want their support networks to look like. This could be through their own experiences, as well as hypothetically who they would be happy to share their emotions with, and the experiences they are going through.

### Family

The majority of the groups primarily identified parents and wider family as the people they would go to when talking about death, dying and bereavement, with many sharing stories of when they have been supported through these difficult situations already: "Talking to my mum helped me to understand why and how it happened with my uncle being murdered. Being 10 and understanding about drugs and alcohol didn't really come into primary a lot. So, my mum filled in those gaps for me and getting ready to go to high school. It helped me a lot to understand that sort of topic". Speaking to family, who already knew them and the situation, was often easier than someone entirely disconnected.

As part of the GDA group, some of the young people shared conversations they had had with their families around their own wishes should anything happen in the future, specifically around funeral plans, as this was something they had been encouraged to think about and communicate. It was clear that they felt death and dying was something to be discussed within families, even when it might be difficult for both parents and young people: "Some parents don't like to talk about their parents when they die but I feel like parents have to be positive for their children. If children want to talk about their grandparents. My gran died when I was four years old, without really knowing her. I've always heard stories. You need your parents to talk about these sorts of things. If your parents are open with you, you're not going to be open in any relationship you have, your parents should treat their children with honesty".

One of the groups also highlighted the importance of family and friends coming together following the passing of someone, to celebrate their lives and remember the positives, as well as supporting each other: "we had a big rocking funeral celebration. He did serve in the army in the first World War, that's how he met my great-grandma and that's how their love story started. They were together 60 years. The friends of my great-grandad they all came and shared their wee stories of them and how he used to stroll along from the pub with his missus".

### Friends

Friends were seen as both positive and negative in terms of who young people might talk to about death, dying and bereavement. Some of the participants felt their friends provided a great support system, being able to discuss the situation they were experiencing without necessarily being directly involved: "Talking to my friends, talking to my boyfriend, outside support coming in. It all helps in some way".

However, this was also seen as a barrier with some young people identifying that they would not want to talk to their friends when they may not have known the person. The issue of privacy was also raised, with the fear that news of someone's passing might be shared online or discussed wider than they would like: "A boy passed away in our primary class and we said not to put it online because not everyone knows, to keep it private until after the funeral. Someone put it on Facebook and lots of people turned up to the funeral and made it public. It didn't sit right with any of us, they wanted it to be private, but it was made into a public affair".

### Professional Support

Some of the young people involved in the workshop sessions had experience of accessing professional services when experiencing bereavement. For those that had accessed these services, they felt it was easier to talk about what they were going through with someone completely detached from the situation, who could offer advice and a listening ear, with no expectations on them to feel or act in a certain way. One participant commented that "It was easier to speak to someone who was a professional. I felt I could speak a lot more, whereas when you speak to a member of the family, it hurts then the same way you're hurting, so you are limited with what you can come out with. With my gran she just closed off her ears, but when speaking to someone that was a professional I just flooded it all out. I could cry, scream, shout, and that was ok, that's progress that you're letting it all out. It feels like a weight off your shoulders that you can just be upset. It's been good".

A few of the participants highlighted that speaking to family members who might also be going through a bereavement meant they did not feel they could openly discuss how they were feeling. They did not want to put more stress on their family members or upset them further, so speaking to a professional provided the space for them to discuss the situation fully, without having to censor their emotions.

Another one of the young people who had made use of professional services had referred themselves, following meeting with their doctor and being put on medication. In this instance they were prescribed medication in the short term to allow them to cope with attending the funeral of a partner, which they saw as a positive, but recognised in the long term they would need further support. They attended bereavement counselling as they found it difficult to fully discuss their emotions with their family and friends. From the positive support they received throughout dealing with death, dying and bereavement, the young person advocated for professional support and not being afraid to ask for help. They recognised that other young people are likely going through similar situations and there is support out there but many do not know how or where to access it: "I just feel as though that see if you're dealing with death, my advice would be, don't be frightened to go to a professional because they will be there to support you in any way they can. Don't be frightened to say and you'll have a lot of support. You're not on your own".

It was also identified by one of the participants that there are certain things they do not want to talk to their parents about, that they'd be more likely to discuss with a professional. Although participants have a very open relationship with their parents, discussions around relationships and their emotions were sometimes easier with professionals.

Although not through their own experience, one of the young people identified support groups as a valuable network to tap into, being able to talk to other people that might be going through similar experiences or have already been through them and can offer advice. They give the opportunity to build relationships and support networks that you may not otherwise have, noting that "what my mum says is when she goes to these groups with similar situations she can help them and they help her, so it builds up relationships".



### Schools

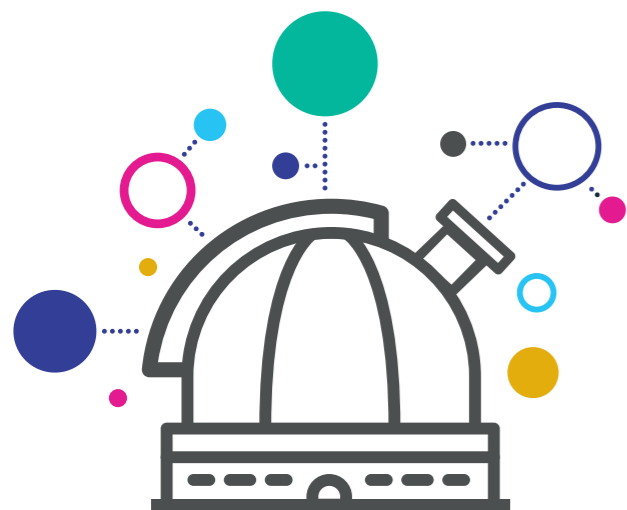
Schools were primarily identified as support mechanisms when a situation affected an entire class or group of pupils, rather than support for individuals. Several participants shared stories of death, dying and bereavement that they experienced through school, both primary and secondary, and how their school supported the pupils. One of the participants told us that their ex-partner, who he was still friendly with, was in an accident and passed away. He shared that the school he attended supported pupils who were affected by what had happened through access to professional services, but he also felt that this should be a matter of course within all schools.

Support in schools was primarily through assemblies, raising awareness of support that is available and services they can access but there was little to no discussion around conversations about the topic generally happening ahead of these experiences.

When thinking about what they might want their support networks to look like, the young people agreed that they would not approach their schools or teachers when talking about death and dying, although they did feel like there should be more general conversations happening, especially at a younger age.

### Information

A lack of information, awareness and understanding for young people was identified throughout each of the groups, from practicalities of the cost of a funeral to awareness of the support available. The young people involved in the workshop sessions identified a need for more information and wider conversations because “there’s lots of things you don’t know. I think there needs to be more available information, especially for those with disabilities. Some people don’t have a family, so what happens to them and they don’t have any money to pay”.



A lack of information, awareness and understanding for young people was identified throughout each of the groups, from practicalities of the cost of a funeral to awareness of the support available.

## Conclusion

Each of the four groups were involved in an exploration workshop to better understand young people’s perceptions and experiences of death, dying and bereavement; the support they may have received to deal with these experiences; and to explore how they might like to talk about the topic sensitively and appropriately. Throughout all of the sessions delivered, the young people openly shared a variety of experiences they had had around the topic.

Opening conversations with some ‘Death Café’ style questions, allowed the young people to ease into the discussions in a more light-hearted way, giving the space for the participants to share as much or as little as they felt comfortable doing. Family pets and the loss of grandparents played a large part of the initial experiences shared within each of the groups, from a very young age, through to much more recently. Many of these experiences were difficult for the young people to go through and discussions extended to a multitude of stories that affected their behaviours and how they viewed their own lives.

While the **majority of the groups primarily identified parents and wider family as the people they would go to for support, this was dependent on their relationship with parents.** Throughout all of the groups it was highlighted that being supported by family, even when family members might also be going through difficult experiences themselves, provided positive role models in their lives and in decision making. In particular the GDA group had conversations around death and dying more freely with their families, discuss their needs and the practicalities should anything happen to them.

**Friends were seen as both a positive support network and a potentially negative influence, specifically in the HMYOI Polmont group.** While the group from the high school in Clackmannanshire identified friends as one of the most important influences in their decision making, and with participants throughout all of the groups identifying friends that had provided support in a variety of ways, **the groups in HMYOI Polmont could clearly see the ways in which friends had encouraged them to make decisions that had long term negative impacts. Across all of the group sessions, partners and youth workers were also identified as positive role models or individuals they could confide in and go to for advice.**

**Professional support services** were made use of by several of the participants who clearly identified **it was easier to talk about what they were going through with someone completely detached from the situation, who could offer advice and an open space to explore their emotions.** Across all of the groups, **schools were primarily identified as support mechanisms when a situation affected an entire class or group of pupils, rather than support for individuals. Support was provided through assemblies,**

**to raise awareness of services they could access. There was little pre-emptive support around death and dying happening ahead of these experiences, which all participants agreed should be happening,** although few participants said they would look to the school when they are experiencing these things.

Along with the support identified by the participants, **a lack of information, awareness and understanding for young people was identified** throughout each of the groups, **from practicalities of the cost of a funeral to awareness of the support available.**

While each young person requires support and information when dealing with death, dying and bereavement, **the support provided must to be specific to their needs, circumstances and attitudes. Young people across all of the groups felt that talking about death and dying is positive, although it was clearly acknowledged that this can be incredibly difficult in different ways for each young person,** with a participant noting that “it’s a hard topic but it’s necessary, you have to be able to talk about it and we don’t talk about it enough”.

**By addressing the need for more information, appropriate support and starting conversations around this topic, young people in Scotland going through these experiences will start to feel more supported throughout.**

To tackle such a sensitive topic with young people, Young Scot was required to work closely with partners and the young people to ensure there was enough support in place before, during and following any delivery. This meant having clear information and advice available, as well as the right people in the room with the capacity to support young people with a variety experiences and needs. Through a flexible, iterative process Young Scot was able to explore the topic of death, dying and bereavement and how young people in Scotland could be better supported throughout these experiences. Even with all the right support in place, this is still a topic that many young people have never explored previously, requiring the time and space to do so sensitively.

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