

Death Matters

Evaluation report on a project run
by Age Concern Birmingham,
September 2015 – May 2016

Funded by the Esmée Fairbairn
Foundation

Project coordinator: Paul Tomlinson(ACB) and Becky Smith

Report Author: Peter Kevern (SU), incorporating material by Paul Tomlinson

August 2016

Executive summary

The Death Matters Pilot ran from September 2015 to May 2016, supported by a grant of £31,791 from the Esmee Fairbairn Foundation. Its purpose was to evaluate whether a series of events based upon the 'Death Café' model may be an effective way to encourage people to talk about their own and others' death in a safe environment. If so, the hope was that this would have a twofold benefit: to reduce the level of anxiety widely reported to be experienced when faced with the prospect of dying; and consequently to provide an occasion to facilitate discussion about practicalities such as funeral planning and End of Life Care.

The key findings from the project are as follows:

1. Experience from the present study has borne out the survey evidence suggesting that people are initially reluctant to talk about the subject, but can be persuaded to 'open up' under the right conditions. Arranging structured events at which people can discuss their concerns around the prospect of their own and others' death in a relatively 'safe' environment has a number of benefits.
2. The basic template, of a public event lasting 1½-2 hours at which refreshments are served and participants are encouraged by a variety of means to broach their concerns about death and dying, deserves to be widely applied across the population, but particularly among those who are facing the prospect of their own death or the death of a loved one in the foreseeable future. Initial fears that participants may be distressed by the process turned out to be unfounded.
3. The success of a session depends to a large extent on the degree to which participants feel relaxed and secure enough to risk discussing the topic. They are therefore very sensitive to the environment: it needs to be warm, welcoming and personal with attention paid to refreshments (especially home-made cake!) and mundane details such as toilet facilities. The coordinator needs to be compassionate and empathic, with both the authority and the flexibility to respond to circumstances as they arise.
4. Participants are not readily recruited by a process of open advertising, but tend to be part of an existing network or social group. Therefore the most effective way of running sessions is to add them on to an existing activity or as part of a group's cycle of events.
5. The evidence suggests that participants are less concerned about the prospect of dying *per se* than they are about its effects on those they will be leaving behind: generally, the content and input needs to be orientated in this way. Specifically, this means that information and services geared to addressing the 'burden' of long-term care; funeral arrangements; wills and probate are likely to be of perennial relevance and interest.

Table of Contents

<u>Executive summary</u>	3
<u>Table of Contents</u>	4
<u>Introduction</u>	5
<u>The story of the project</u>	7
<u>Evaluation</u>	8
Sources of information	8
Findings	8
<i>Recruitment and marketing</i>	8
<i>Organisation/delivery</i>	11
<i>Attendees and their anxieties</i>	12
<u>Conclusions of the evaluation</u>	14
<u>Recommendations</u>	15
<u>Appendices</u>	17
Appendix 1: Drafts of adverts.....	17
Appendix 2: Session plan	19
Appendix 3: the questionnaire tools	21
Appendix 4: DAS/DAQ summary results	25
Appendix 5: Best practice guide	27

Introduction

The Death Matters Pilot ran from September 2015 to June 2016, supported by a grant of **£31,791** from the Esmee Fairbairn Foundation. Its purpose was to evaluate whether a series of events based upon the 'Death Café' model may be an effective way to encourage people to talk about their own and others' death in a safe environment. If so, the hope was that this would have a twofold benefit: to reduce the level of anxiety widely reported to be experienced when faced with the prospect of dying; and consequently to provide an occasion to facilitate discussion about practicalities such as funeral planning and EoLC.

The need for new initiatives to encourage discussion and practical planning around death is amply demonstrated in the literature. According to recent surveys, less than half of UK adults have made a Will (<https://www.moneymarketing.co.uk/more-than-half-of-uk-adults-have-not-made-a-will/>) and less than a third of people in the UK have discussed their wishes around dying (<http://www.dyingmatters.org/page/survey-reveals-our-reluctance-discuss-own-death>). .

Although the reasons for this lack of preparedness are clearly complex, the prevailing cultural taboos concerning talking about death in public clearly contribute to the situation. According to the same survey, 8 out of 10 participants said that people in Britain are uncomfortable talking about death and dying, even though more than two thirds of the same people say they themselves are comfortable talking about the subject.

There has been a few initiatives which attempt to address this reticence and the practical consequences that follow by fostering open, shared conversations about death and dying in public contexts. The largest and best-known of these has been the 'Death Cafe' movement (www.deathcafe.com) According to their own figures, they have to date supported 3408 events in 33 countries and provide support for local, self-starting groups to organise open events for any individuals interested in discussing death and dying. Their model is deliberately 'light touch', with little structure or management of an event beyond a little light oversight.

Another initiative which has drawn upon the Death Café model is 'GraveTalk' in the Church of England (http://www.staffs.ac.uk/academic_depts/health/research/journal_of_new_writing_in_health_and_social_care/journal_of_new_writing_in_health_and_social_care_issue_2.jsp) which encourages and supports local congregations to run café-style events in, clearly, a specifically church-based context (<https://churchofenglandfunerals.org/gravetalk/>). One distinctive feature of this model is to use a device, Conversation Cards, to facilitate conversation and interaction among strangers, and a refinement of this approach was incorporated in the present pilot.

The intention of the current project was to learn from the Death Café and GraveTalk experience but to adapt it to a different set of circumstances in which:

- It would not be aimed at 'all comers' (Death Café events are often dominated by younger participants) but would be geared towards the concerns and needs of older people
- It would not be associated with a particular religious or secular context but instead be offered under the auspices of Age Concern Birmingham (ACB)
- It would make links as appropriate with services offered by or through Age Concern or its trusted partners, such as the Will Writing service and funeral planning

The strategic significance of this initiative within the work of ACB lies in the fact that inadequate preparation for death is the source of much avoidable suffering for older people and their relatives. As stated in the funding application,

Many of the services which we currently run are reactionary in nature due to this lack of planning. Services such as the Carers' Hub, our legal services and our Debt & Welfare project all deal with the impact of people not having thought or planned for death and the impacts that this can have on those around them and/or their estate. A pro-active approach would reduce anxiety and the resources expended in trying to resolve issues for all concerned.

The present pilot was set up to establish whether, in the event, the offering of café-style opportunities to discuss death and dying could realise some of this potential benefit

The story of the project

The project as originally conceived envisaged a series of 1.5 – 2 hour discussions at a range of times and in a range of locations. The project was intended to deliver 40 sessions throughout the year to a total of 480 people. Recruitment was both via existing organisations and advertising within a local area to get people to attend. The intention was to build in flexibility: discussion, location, time and topic were adjusted throughout the period to ensure that delivery was effective at getting the right message across to people within the right context.

In the original proposal, Templer's 'Death Anxiety Scale' would be used to assess people prior to the discussion and a sample contacted after 3 months to revisit the test and find out what practical steps people had taken as a result of the talk.

The outputs from this project were therefore to be constituted by the delivery of the 40 sessions, evaluative evidence either supporting or not supporting attitudinal change and the production of a best practice guide based on this evidence.

The original application stressed the importance of breadth, seeking to apply the model to a range of participant groups. It also stressed flexibility, with ongoing evaluation and adaptation within the course of the pilot in order to evolve an effective and widely applicable template for future work by ACB and other organisations. Consequently, the coordinators reflected after each event and made changes as they went along. Key areas for exploration and development were:

- Advertising and recruitment. A range of different advertising media were explored, and different types of flyer and poster.
- The timing, location and organisation of events
- The role of the moderator/leader of the event along with the appropriate use of tools such as the Conversation Cards
- Ways to build upon or enhance the event with the presence of information or service providers; and followup of participants

Inevitably, between the planning and the delivery of the project a number of key changes were made. Because there was a change of coordinator at the end of the calendar year, the start of sessions was slightly delayed and the majority of activity took place towards the end of the planned period. Furthermore, it turned out to be more difficult to attract participants to the sessions than had been hoped, so although more than 40 sessions were planned more than 50% of them had to be cancelled due to lack of support. Finally, it became clear that the original pre-post study design using Templer's Death Anxiety Scale administered at the session and three months later was unworkable, given the numbers involved: it would require the coordinators to maintain contact with participants who were relative strangers over a protracted period after the session, and just the activity of administering questionnaires at two time points to a small sample would introduce distortions that would render the data meaningless. Consequently, we decided to supplement the Death Anxiety Scale (DAS) with another validated measure, the Death Anxiety Questionnaire (DAQ); but to administer the measure only once, at the session itself (see appendix 3 for questionnaire details).

Evaluation

Sources of information

- Recruitment and participant information: number of sessions, participant numbers and demographics, responses to recruitment initiatives such as advertising
- Project coordinators' 'Lessons learnt' feedback on what worked in the sessions, the composition of the group and qualitative assessment from participants
- comments from participants (via project coordinators)
- DAQ and DAS scores

Findings

Recruitment and marketing

The initial marketing strategy was to promote the events via social media (Facebook and Twitter) and the ACB website; and to design flyers, tri-fold leaflets and posters in-house. The thinking behind this was that it would be possible to trial different background images, and experiment with the wording. By identifying what worked and what didn't, insights would be gained on the issues and concerns which the sessions would be best suited to address. Members of staff reviewed various posters to identify the poster/wording most relevant to the subject matter.

However, Twitter, Facebook (social media) and the ACB website (see e.g. <https://www.ageconcernbirmingham.org.uk/Blog/death-matters-mere-green>) postings did not seem to generate interest in Death Matters; and once the image and the wording was agreed for the advertising material, it became apparent that there was need to get further flyers, posters, etc. professionally designed.

Once engaged, the designer designed a tri-fold leaflet, a flyer and a pop up banner. Instantly it was noticeable that the quality of these (compared with the in-house versions) was far superior and commanded the confidence of staff (see appendix 1).

The key lessons from this iterative, collaborative process were that a marketing strategy needs to be developed earlier in the life of the project, and engage professional help from the start. However, as shown in the demographic data below, there is little evidence that the marketing campaign generated many new participants. By the end of the project, there was some anecdotal evidence that individuals were attending because they had heard of the sessions by 'word of mouth', but this process develops too slowly to be of much use for recruiting within the lifetime of the project.

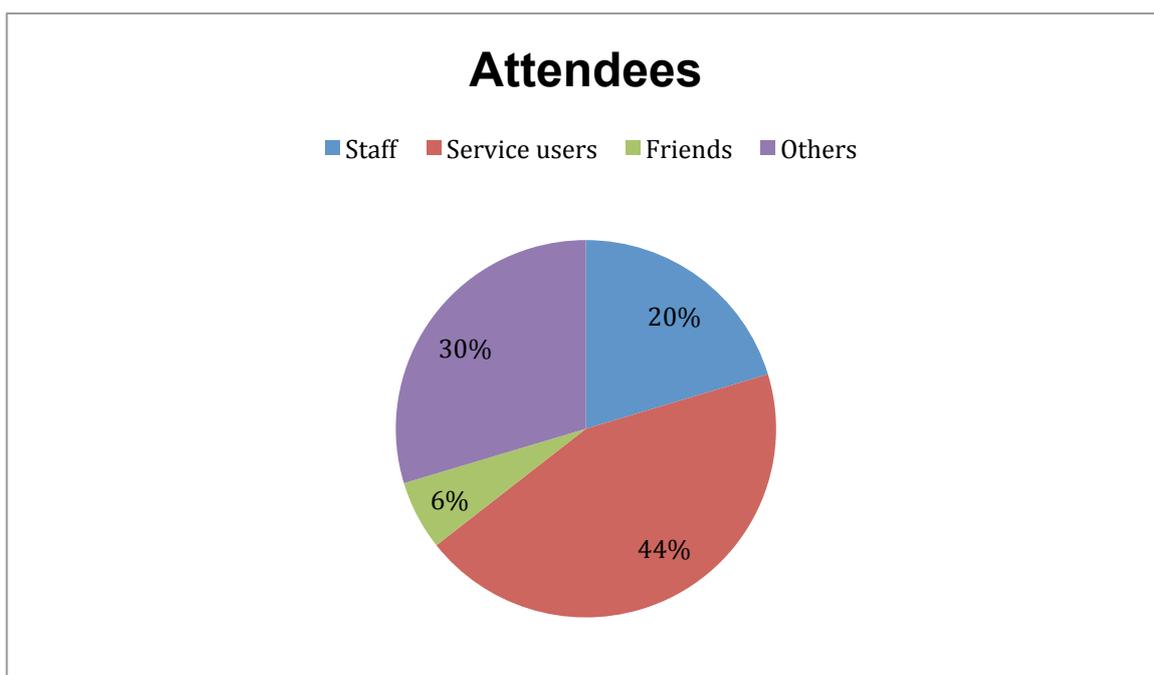
Demographic data

By the close of the project, the team had organised forty-three sessions (of which 17 ran and 26 had to be cancelled). A total of 118 people attended the sessions. This worked out at an average of just under 7 per session delivered.

Of the sessions cancelled,

- 21 were cancelled because of lack of interest,
- One due to ill health of the session leader,
- One because of no show of participants
- One session was moved to a different day,
- Two because of conflict with schedule

Further review of the attendees highlighted the following trend:

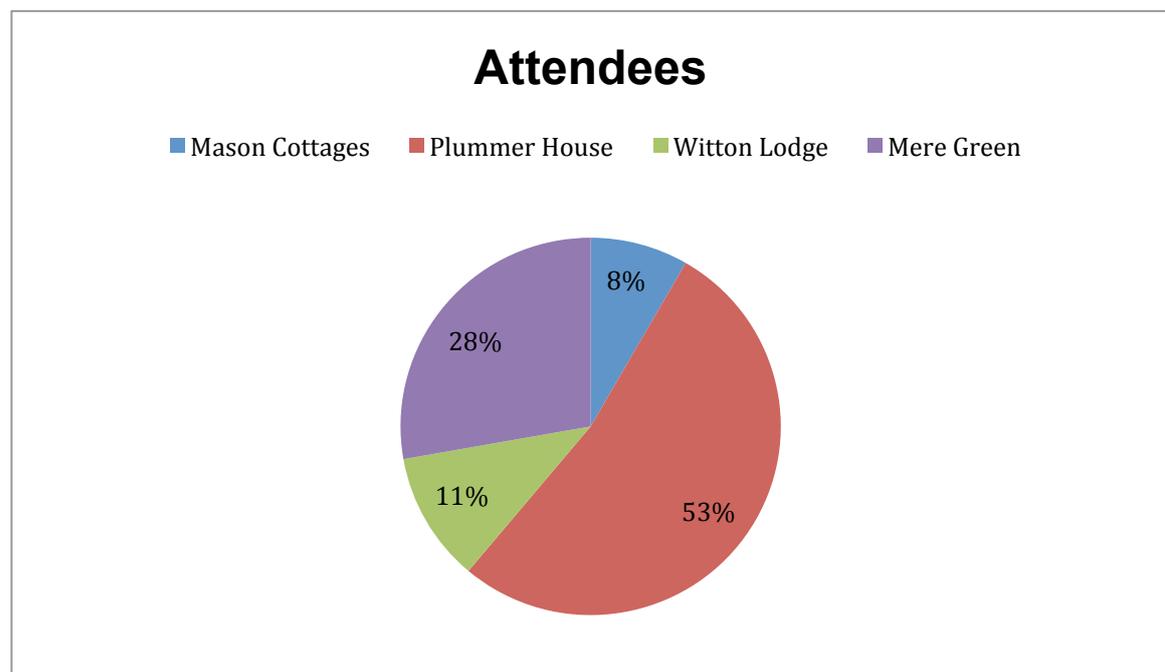


- Twenty-three members of Age Concern Birmingham (ACB) staff attended
- Fifty-two people from existing groups that utilise the ACB centres (Hawkesley and Moorfield)
- Seven people who were personal friends of the coordinator attended.

There are 36 people classified in the above pie chart as others, these are mainly residents and staff of such locations as:

- Mason Cottages, Orphanage Road, Erdington. B24 0AL. – three attendees.
- Plummer House, Aston – 19 attendees.
- Witton Lodge – 4 attendees.

Additionally, ten people attended our Mere Green sessions who had no other known connection to the centre or ACB.



Conclusions from data on recruitment and attendees

The experience of recruitment and participation outlined above reinforces a finding of the GraveTalk project, that conversations on death and dying are very difficult to establish by a process of open recruitment: the subject is a threatening one, and people need to feel 'safe' before they are prepared to expose themselves to it. Thus, most of the events which were planned to recruit through open advertising had to be cancelled due to lack of interest. The exception (although here there was also a low take-up) was the series of 7 sessions offered at the Mere Green Library.

Generally, it seems that sessions were best attended and worked best if the participants already knew each other. The best-attended sessions tended to be those where there was an existing group, who either added it to the end of one of their existing activities or scheduled it into their programme. There was

some evidence that if the pilot had run for longer an increasing number of participants would have been recruited by 'word of mouth', but it is difficult to evaluate the likely contribution of this phenomenon over time.

One practical implication of this finding is that it is an inefficient use of energy and resources to attempt to reach out to the community as a whole through generalised advertising: personal connections and existing groups are more likely to provide a basis for this type of intervention.

Organisation/delivery

Once participants had been attracted to the sessions, they appear to have been a success. It is clear from the coordinator's reflections after each one that every session was different, with a wide range of concerns and variable dynamics. Consequently, within the range of possible activities and emphases outlined in the template (see appendix 2) it was necessary for the coordinator to demonstrate a good deal of flexibility and ingenuity. If the process is to have wide appeal, this flexibility seems to be an inescapable requirement.

Regarding the process, as in the GraveTalk findings the provision of cake proved an important symbol of care for the participants.¹ The decision to aim for a session of 1½ - 2 hours proved appropriate, and conversation cards seemed to work well as an icebreaker. Thereafter, different groups required different levels of direct input. Factual input was appreciated on details about how different cultures deal with death; and on new developments in alternative funerals.

Conclusions from reflections on individual sessions

The basic model of a one-off session of 1½ - 2 hours with the provision of good-quality refreshments and a range of devices such as conversation cards to stimulate discussion has been shown to work well.² It was also useful to have a framework or template of the areas that might be covered and the methods that might be used.

Within that framework, it proved to be indispensable to have a coordinator who could adapt materials and methods freely to respond to the range of concerns, personalities and circumstances represented. This suggests that it would be a mistake to attempt to prescribe to precisely what such an event is for and how it might be conducted.

¹ See the analysis of GraveTalk findings in Kevern, P., & Sanders, J. (2015). 'Death-confident congregations'? Lessons from the GraveTalk Pilot. *Journal of New Writing in Health and Social Care*, 1(2), 21-30, obtainable from http://www.staffs.ac.uk/academic_depts/health/research/journal_of_new_writing_in_health_and_social_care/journal_of_new_writing_in_health_and_social_care_issue_2.jsp

² See also Sabatino, C. P. (2014). Advance care planning tools that educate, engage, and empower. *Public Policy & Aging Report*, 24(3), 107-111. Obtainable from <http://ppar.oxfordjournals.org/content/24/3/107.short>

Finally, there remains a question about how determinate information (e.g. on wills or advanced care plans) is integrated with a predominantly informal and participant-led conversation.

Attendees and their anxieties

The original application stressed the importance of breadth, seeking to apply the model to a range of participant groups. It also stressed flexibility, with ongoing evaluation and adaptation within the course of the pilot in order to evolve an effective and widely applicable template for future work by ACB and other organisations. This aim was in some tension with the needs of the evaluation phase of the project, because robust evidence is best gathered in the context of minimal change, as results are repeated.

For this reason, a decision was made early in the life of the project to abandon the 'repeated measures' aspect of the research design: instead of attempting to measure participants' scores on Templer's Death Anxiety Scale at the time of the intervention and at 3 months, participants were invited to fill out a more extensive questionnaire once only, at the time of the event (see appendix 3). This meant that we did not have quantitative evidence for a reduction in death anxiety as a result of the intervention. Instead, the data gave insights into the issues about which participants were most anxious, and therefore the ones which current and future events should be tailored to address.

Of those who attended, 84 people (74%) completed and returned the questionnaire form a possible maximum of 118. Some preferred to take them home with them to complete, whilst others did not want to or, in the case of the session for the TEDs group (32 attendees), some took the form away with them because their transport had turned up. A number of people were unable to complete the form (for example, because of poor sight) but whenever possible assistance was offered to assist people with the paperwork.

The Death Anxiety Questionnaire (DAQ) was generally filled in comprehensively and thoughtfully, as far as can be judged. It was scored on a scale of 0 to 2, corresponding to the answers 'Not at all', 'Somewhat' and 'Very Much'.

The Death Anxiety Scale (DAS) had the option only for False/Disagree (2) and True/Agree (1), and the answers needed more careful treatment. In the first place, a number of the questions were reverse-scored, and needed to be adjusted for the final scoring. Secondly, it was noted that the Templer questionnaire appeared to have been filled out carelessly in some cases: these were identified by checking opposite answers for questions 1&5, which were functionally equivalent but with opposite answers. The questionnaires in which contradictory answers were given to these indicator questions

amounted to 28/82 (34%) so a significant potential error. In order to guard against this error, the questionnaires displaying this characteristic were removed and the analysis re-run, but the final result was unchanged.

In both cases, scores were totalled across all respondents for each question. This yielded a mean. In addition, the proportion of respondents for each question who recorded the maximum score was recorded, to gain a measure of intensity of feeling (see Appendix 4). In the event, on the DAQ those with the highest means had the highest number of maximum scores; and on the DAS those with the lowest means had the highest number of minimum scores, so the two methods of recording significance concurred.

For the DAQ, the responses indicating strongest death anxiety responses were represented by high scores. The 3 highest scores for the scale were:

- 4 – Does it upset you to think others may see you suffering before you die?
- 8 – Does the thought bother you that you might lose control of your mind before death?
- 12 – Does the thought of leaving loved ones behind when you die disturb you?

The lowest scores (low anxiety) were for:

- 13 – Do you worry that those you care about may not remember you after your death
- 10 – Does it worry you that your instructions or will about your belongings may not be carried out after you die?
- 14 – Does the thought worry you that with death you may be gone forever?

For the DAS, the responses indicating strongest death anxiety responses were represented by low scores. The 3 lowest scores for the scale were:

- 9 – I fear dying a painful death
- 12 – I often think about how short life really is
- 15 – I feel that the future holds nothing for me to fear (reverse value)

(Question 3 gave a low mean score, but this disappeared when the contradictory questionnaires were removed)

The highest scores (low anxiety) were for:

- 4 – I dread to think about having an operation
- 10 – The subject of life after death troubles me greatly
- 14 – the sight of a dead body is horrifying to me

Conclusions from data on participants' anxieties

It is not surprising that people are afraid about death, as this is perhaps a human universal. However, the survey usefully reveals what most concerns people about the prospect of death. Their concerns are not primarily about how they will 'live on', whether in people's memories, in the carrying out of their wishes or through a religious belief. They are most worried about the effect that their death and the events leading up to it will have on those closest to them.

This finding has an immediate practical implication if the hope is that this type of event may lead to better promotion of schemes to prepare for death such as Advance Care Plans , Will Writing and funeral plans. It suggests that in order to successfully promote such schemes, they will need to be 'marketed' in terms of what they can do for relatives (reduced stress, greater security etc) rather than how they will perpetuate the individual's wishes.

Conclusions of the evaluation

This pilot project has yielded much valuable information regarding the potential of lightly-structured, medium-length events presented with the express intention of discussing death and dying to address peoples' anxieties, encourage them to share their concerns and point them towards information and resources that will help them to prepare for their own and others' death. There are good reasons to conclude that events of this type, if planned wisely and delivered well, can contribute to addressing both the emotional and practical needs of people at the end of life and their relatives.

Having said that, it is clear that some of the activities engaged in as part of this pilot were more successful than others in attracting participants and addressing their needs. Summarising the results of the previous sections we may say that the following are rewarding of the time, money and energy invested:

- Recruitment through personal contacts, existing groups or collaborations
- The provision of good-quality refreshments and a welcoming overall environment
- A range of available tools such as conversation cards to stimulate discussion
- a framework or template of the areas that might be covered and the methods that might be used.
- a coordinator who could adapt materials and methods freely to respond to the range of concerns, personalities and circumstances represented.
- Some information available about possible ways to respond to financial and social concerns

- An overall approach that addresses participants' concerns for the loved ones they will be leaving behind

Conversely, the following proved to offer a poor return on the investment:

- General, impersonal advertising and attempts at open recruitment
- The inflexible use of a template or process regardless of the demographics and concerns of the participant group
- An emphasis on the individual's fears for themselves or their reputation after they have died

Recommendations

(These will form the basis of *Planning an event to talk about death and dying: A Good Practice Guide*, to be published on the ACB website)

1. Experience from the present study has borne out the survey evidence suggesting that people are initially reluctant to talk about the subject, but can be persuaded to 'open up' under the right conditions. Arranging structured events at which people can discuss their concerns around the prospect of their own and others' death in a relatively 'safe' environment has a number of benefits. Psychologically, anxieties tend to be reduced in the simple act of talking about them, but in addition, participants are then better placed to come up with their own solutions for some of their concerns (for example, by deciding to write a Will to protect their dependants when they die). Furthermore, charities and private bodies may offer services (such as Advance Care Planning or funeral plans) to which concerned participants can be directed for help.
2. The success of a session depends to a large extent on the degree to which participants feel relaxed and secure enough to risk discussing the topic. They are therefore very sensitive to the environment: it needs to be warm, welcoming and personal with attention paid to refreshments (especially home-made cake!) and mundane details such as chairs and toilet facilities. The coordinator needs to be compassionate and empathic, with both the authority and the flexibility to respond to circumstances as they arise.
3. The basic template, of a public event lasting 1½-2 hours at which refreshments are served and participants are encouraged by a variety of means to broach their concerns about death and dying, deserves to be widely applied across the population, but particularly among those who are facing the prospect of their own death or the death of a loved one in the foreseeable future. Initial fears that participants may be distressed by the process turned out to be unfounded. However, it is important that the template is applied flexibly and creatively by the event coordinator, so as to respond to the needs of those who turn up on the day. Similarly although a range of devices (such as the

conversation cards, or information about other cultures) may be made available, the question of whether to use them (and if so, in what way) needs to be decided on the spot.

4. Notwithstanding the need for flexibility, a number of specific lessons have been learned from this pilot which appear generalizable:
 - a. Open advertising does not generate a significant number of participants in the short-term. There is some evidence that, given long enough, it may contribute to the recruitment of participants by word-of-mouth.
 - b. Generally, people are reluctant to attend a session on such a potentially threatening topic unless they know at least some of the other participants: attention needs to be paid to existing networks of relationships. Therefore the most successful events are those that build on an existing group: either by timetabling the session to follow on from a regular activity; or to replace it; or by tapping into an existing network of (for example) users of the building.
 - c. The evidence suggests that participants are less concerned about the prospect of dying *per se* than they are about its effects on those they will be leaving behind: generally, the content and input needs to be orientated in this way. Specifically, this means that information and services geared to addressing the 'burden' of long-term care; funeral arrangements; wills and probate are likely to be of perennial relevance and interest

Appendices

Appendix 1: Drafts of adverts

Why not come along to one of our sessions?

Our free sessions are a safe space for you to talk freely about what matters to you.

To book a place call Paul Tomlinson on: 0121 362 3650

or email: P.Tomlinson@ageconcernbirmingham.org.uk

AGEconcern
Birmingham

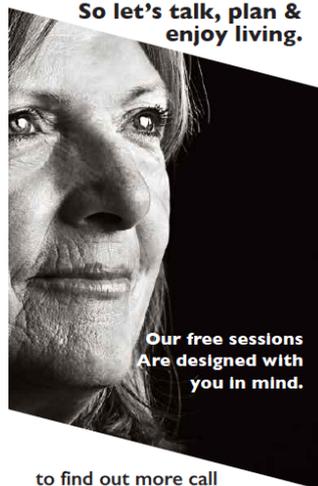


Age Concern Birmingham
76-78 Boldmere Road
Boldmere
Sutton Coldfield
B73 5TJ

Phone: 0121-362-3650
E-mail: info@ageconcernbirmingham.org.uk
Charity No. 518610

AGEconcern
Birmingham

**Death Matters.
So let's talk, plan &
enjoy living.**



**Our free sessions
Are designed with
you in mind.**

to find out more call
Paul Tomlinson on:
0121 362 3650

Email: P.Tomlinson@ageconcernbirmingham.org.uk

Talk, Plan & Live

Our sessions are:

- About death, dying & living
- A space to talk freely & openly
- About what matters to you
- Supportive & friendly
- Over a cup of tea or coffee
- Free of charge

Some sessions may focus on starting sensitive conversations with relevant people.

They are an open conversation about getting older, death and dying.

During these sessions people may wish to share their personal thoughts and feelings, and draw on their own experience of life.

Venues, Dates & Times

Hawkesley Community Centre
B38 9RN
Every Thursday from 3rd March
2pm - 4.30pm

Moorfield Hall Community Centre
B34 6QX
Every 2nd Tuesday from 8th March
1pm - 4pm

Mere Green Community Centre
B75 5BT
Every Monday from 4th April
(excluding Bank Holidays)
until 13 June 2016
3pm - 5pm

Thimblemill Library, Smethwick
B67 5RJ
Mon. 21/03/16 2-30pm - 4-30pm
Wed. 06/04/16 5pm - 7pm
Fri. 29/04/16 Midday - 2pm
Fri. 27/05/16 2-30pm - 4-30pm

About Age Concern

Our services include

- Advice
- Information
- Signposting services
- Will writing
- Power of attorney & other legal services
- Funeral plans
- A range of products & services via Advant-age
- Firstcall (help with home maintenance or repair)
- Care and domestic support
- Support for carers
- Insurances
- Door-to-door holidays

Please feel free to call us at Age Concern Birmingham on:

0121 362 3650

Visit our website:

www.ageconcernbirmingham.org.uk

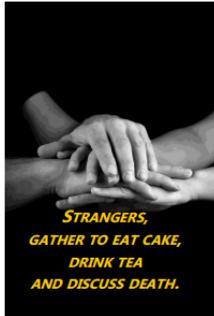
AGEconcern
Birmingham

In-house design

**WE'RE RUNNING A
NUMBER OF SESSIONS LO-
CALLY.**

**TO BOOK A PLACE CALL:
PAUL TOMLINSON ON:
0121 362 3650**

**or, Email:
P.Tomlinson@ageconcernbirmi
ngham.org.uk**



Funded by:



Age Concern Birmingham
76-78 Boldmere Road,
Boldmere,
Sutton Coldfield,

Phone: 0121-362-3650
E-mail:
info@ageconcernbirmingham.org.uk

DEATH MATTERS



**A FREE SESSION
TALKING ABOUT THE
THINGS THAT
MATTER TO YOU.**

DEATH MATTERS

FREE SESSION ON DEATH AND DYING

OUR SESSIONS ARE FRIENDLY, FREE OF CHARGE, SUPPORTIVE, OPEN TO EVERYONE, A SAFE SPACE TO TALK FREELY ABOUT WHAT MATTERS TO YOU, WHAT TO SAY TO OTHERS, WHERE TO FIND HELP WITH PLANNING.

THEY ARE AN OPEN CONVERSATION ABOUT GETTING OLDER, DEATH AND DYING.

DURING THESE SESSIONS PEOPLE MAY WISH TO SHARE THEIR PERSONAL THOUGHTS AND FEELINGS, ASK QUESTIONS AND DRAW ON THEIR OWN EXPERIENCE OF LIFE. EVERYONE WILL BE EXPECTED TO RESPECT THE TRUST THAT WE PLACE IN ONE ANOTHER FOR THE DURATION OF THIS TIME, AND AFTERWARDS.

TALK, PLAN, LIVE.

EACH SESSION WILL BE DIFFERENT AND SOME SESSIONS MAY FOCUS ON STARTING SENSITIVE CONVERSATIONS WITH RELEVANT PEOPLE; THE IMPORTANT, PRACTICAL STEPS TO TAKE TO ENSURE YOUR END-OF-LIFE WISHES ARE MET AND SORTING OUT THE NECESSARY DETAILS, SUCH AS FUNERAL PLANS, TO ENABLE YOU TO LIVE LIFE TO THE FULL, WITH PEACE OF MIND.



*TALKING
ABOUT DEATH
DOESN'T
BRING DEATH
CLOSER
IT'S ABOUT
PLANNING FOR
LIFE.*

AGE CONCERN

ALONGSIDE OUR ADVICE, INFORMATION AND A SIGNPOSTING SERVICES, WE ALSO OFFER:

- WILL WRITING
- POWER OF ATTORNEY & OTHER LEGAL SERVICES
- FUNERAL PLANS
- A RANGE OF PRODUCTS & SERVICES VIA ADVANT-AGE
- FIRSTCALL (HELP WITH HOME MAINTENANCE OR REPAIR)
- CARE AND DOMESTIC SUPPORT
- SUPPORT FOR CARERS
- INSURANCES
- DOOR-TO-DOOR HOLIDAYS

PLEASE FEEL FREE TO CALL US AT AGE CONCERN BIRMINGHAM ON :

0121 362 3650.

Professionally designed version

Appendix 2: Session plan

Session Plan

In essence these sessions have:

'No agenda, no themes and no objectives!' – This is participant lead and the content may change.

Facilitation Talk/Notes

Elements to include

The basic elements are:

Welcome and introduction –

Any housekeeping matters – toilets, fire alarm, toilets.

A bit about Age Concern – who we are...

Introduction to Death Matters...

Explanation of purpose of the session...

We are meeting for an open conversation about getting older, death and dying. During which people may wish to share their personal thoughts and feelings, ask questions and draw on their experience of life.

Please respect the trust that we place in one another for the duration of this time, and afterwards. If you do refer back to the contribution that anyone else made, do so in a generalized manner that does not identify the person.

If anyone gets upset or distressed, we will stop and / or take a break.

Advise that some may be contacted for a short follow up telephone interview by Staffordshire University people who are doing the evaluation.

Outline the proposed timetable, in terms of available breaks...interval / refreshments / comfort break some stage – this could depend on how things are going.

Equipment:

Facilitators: - TWO – see bid.

What to take/order - Refreshments:

Tea, Coffee, Sugar, Milk and Cake and Biscuits. – Some venues may provide these – others will charge, and may charge for space (need an agreed budget – venues vary and so will costs). Whilst at other venues we'll have to take along the refreshments.

Feedback forms/questionnaires (2 per attendee).

Age Concern handouts – Wills, Trusts, etc.

Q cards from Stafford Uni.

Pens for completing Feedback forms/questionnaires (2 per attendee).

Contingency:

Talk about what people don't want – often easier to discuss the things people don't want to happen...

Q Cards... there's five different questions /consider using these as Ice Breakers...if things aren't moving along.

Considerations:

Feedback the identified priorities and (depending upon their number and relative strength) propose and secure agreement from group as to a running order

Q & A before the break and at the end; plus, our availability afterwards

Feedback forms

Advise that some may be contacted for a short follow up telephone interview by Staffordshire University or by someone from Age Concern³ people who are doing the evaluation.

³ Requirements may change from Staffordshire Uni. to Age Concern Birmingham

Appendix 3: the questionnaire tools

About Age Concern

Age Concern Birmingham is a local charity, committed to the people and communities surrounding Birmingham. We started delivering services over 25 years ago and since then, with the help and support of local people we have grown, whilst always retaining our focus on excelling in meeting the needs of older people and others in need.

We are particularly adept in the provision of direct services for older adults but recognise the benefits of a holistic approach. In supporting those who care for older adults and those who may experience hardship in later life, we can make a positive contribution to the lives of current and future older adults.

We are rooted in the ethos of being a local charity for local people. We will always strive to retain our individuality and we are not aligned to, or any part of a large organisation. This allows us to be responsive, flexible and close to the ground.

DEATH MATTERS

Talking about death does not bring it any closure. It is about planning for life.

Nevertheless, it is a subject you may feel like raising with those close to you. There may be practical matters to discuss — wills, care arrangements — as well as emotional matters. However, if you find ways to break the silence, it can take a great weight off your shoulders.

Our free sessions are a safe space to talk freely about what matters to you. They are friendly, supportive, and open to everyone to discuss what to say to others, and where to find help with planning.

We would like to ask you to complete the following questionnaire, which will help us build a better understanding of how people view death and dying. The information that you provide will help us improve how we represent and learn.

Many thanks for your participant in this.

Your Contact Details – Please complete.

Name:

Address:

Phone number:

Email address:

CONSENT TO BE CONTACTED FOR FUTURE RESEARCH

As part of this project, Age Concern Birmingham would like to do a follow up telephone call. This will allow us to gain a better understanding of any changes that have occurred as a result of this session and our evolution of these sessions.

I give my consent to be contacted

I give my consent to be contacted Yes / No

If **yes**, then:

Preferred contact method (please tick):

..... Telephone

..... Email

..... Letter

Section one.

DIRECTIONS: Please indicate your age and gender below:

Age Band (please tick one of the following bands)

20-29	30-39	40-49	50-59	60-69	70-79	80+
-------	-------	-------	-------	-------	-------	-----

Gender **(please tick one of the following bands)**

Male	Female	Prefer not to say
------	--------	-------------------

Section Two⁴

Instructions: For each of the following items, indicate your response according to the following scale.

0 = Not at all.	1 = Somewhat.	2 = Very much.
Item	Question	Scale (0,1 or 2)
1	Do you worry about dying?	
2	Does it bother you that you may die before you have done everything you wanted to do?	
3	Do you worry that you may be very ill for a long time before you die?	
4	Does it upset you to think others may see you suffering before you die?	
5	Do you worry that dying may be very painful?	
6	Do you worry that the persons closest to you won't be with you when you are dying?	
7	Do you worry that you may be alone when you are dying?	
8	Does the thought bother you that you might lose control of your mind before death?	
9	Do you worry that expenses connected with your death will be burden to other people?	
10	Does it worry you that your instructions or will about your belongings may not be carried out after you die?	
11	Are you afraid that you may be buried before you are really dead?	
12	Does the thought of leaving loved ones behind when you die disturb you?	
13	Do you worry that those you care about may not remember you after your death?	
14	Does the thought worry you that with death you may be gone forever?	
15	Are you worried about not knowing what to expect after death?	

⁴ Death Anxiety Questionnaire

Section Three⁵

If a statement is true or mostly true as applied to you, circle "T". If a statement is false or mostly false as applied to you, circle "F".

Item	Question	TRUE	FALSE
1	I am very much afraid to die.	T	F
2	The thought of death seldom enters my mind.	T	F
3	It doesn't make me nervous when people talk about death.	T	F
4	I dread to think about having to have an operation.	T	F
5	I am not at all afraid to die.	T	F
6	I am not particularly afraid of getting cancer.	T	F
7	The thought of death never bothers me.	T	F
8	I am often distressed by the way time flies so very rapidly.	T	F
9	I fear dying a painful death.	T	F
10	The subject of life after death troubles me greatly.	T	F
11	I am really scared of having a heart attack.	T	F
12	I often think about how short life really is.	T	F
13	I shudder when I hear people talking about a World War III.	T	F
14	The sight of a dead body is horrifying to me.	T	F
15	I feel that the future holds nothing for me to fear.	T	F

⁵ Death Anxiety Scale

Appendix 4: DAS/DAQ summary results

Section 2: Death Anxiety Questionnaire is from Conte, H.R., Weiner, M.B. and Plutchik, R., 1982. Measuring death anxiety: conceptual, psychometric, and factor-analytic aspects. *Journal of personality and social psychology*, 43(4), p.775.

Section 3: the Death Anxiety Scale (DAS) from Templer, D.I., 1970. The construction and validation of a death anxiety scale. *The Journal of general psychology*, 82(2), pp.165-177.

Section 2 was generally filled in comprehensively and thoughtfully, as far as can be judged. Scored on a scale of 0 to 2

Section 3 scored as False (1) or True (2). There is some reverse-questioning which was adjusted before analysis. Values were reversed values for questions 2,3,5,6,7,15. Non-answers are scored at 1.5, since in most cases respondents indicated (by a questionmark, a line between two answers or another device) that they were 'on the fence'.

In both cases, scores were totalled across all respondents for each question. This yielded a mean. In addition, the proportion of respondents for each question who recorded the maximum score was recorded, gain a measure of intensity of feeling.

In addition, it was noted that the Templer questionnaire was appears to have been filled out carelessly in some cases, were identified by checking opposite answers for questions 1&5, which were functionally equivalent but with opposite answers. The questionnaires which amounted to 28/82, or 1/3 of responses, so a significant potential error. These responses were removed and the analysis re-run, but the final result was unchanged.

The table below gives, for each question, the mean score and the percentage indicating the maximum (2 points). For the Death Anxiety Scale, there is an additional measure which excludes respondents who gave contradictory answers to questions 1 and 5

	Question	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
DAQ	Me an	0.16	0.946	1.08	1.321	0.884	0.884	0.804	1.223	1.000	0.348	0.473	1.134	0.25	0.241	0.357
	% ma xim um	8.9	28.6	30.4	44.6	23.2	23.2	17.9	44.6	30.4	5.4	14.3	41.4	3.6	8.9	7.1

DAS, all respondents	Mean	1.784	1.488	1.348	1.76	1.507	1.61	1.519	1.483	1.384	1.867	1.501	1.434	1.758	1.8	1.619
	% Maximum	71.8	49.4	63.5	69.4	47.1	36.5	45.9	42.4	31.8	81.2	45.9	38.8	68.2	74.1	35.3
DAS, excluding contradictory	Mean	1.718	1.545	1.705	1.773	1.673	1.464	1.618	1.464	1.4	1.857	1.518	1.402	1.722	1.804	1.4
	% Maximum	69.9	53.6	69.6	75	64.3	42.9	58.9	44.6	35.7	85.7	51.8	39.3	69.6	80.4	35.7

Appendix 5

Planning an event to talk about death and dying: A Good Practice Guide

As a society, we are not very good at talking about death and dying. According to recent surveys, less than half of UK adults have made a Will (<https://www.moneymarketing.co.uk/more-than-half-of-uk-adults-have-not-made-a-will/>) and less than a third of people in the UK have discussed their wishes around dying (<http://www.dyingmatters.org/page/survey-reveals-our-reluctance-discuss-own-death>).

This is particularly an issue as people approach the end of life: appropriate preparations are not made, leading to suffering for them and their loved ones.

One way in which several different organisations have tried to address this shortfall is by putting on group events where people have an opportunity to talk about death and dying in a supportive environment – for example, the death café movement (www.deathcafe.com) and the Church of England's 'GraveTalk' project (<https://churchofenglandfunerals.org/gravetalk/>)

In 2016, ACB ran a pilot project funded by the Esmee Fairbairn Foundation in order to explore ways to encourage older people and their loved ones to talk about preparing for dying: about their anxieties, but also about practical matters such as Advanced Care Plans, Wills and Funeral preferences. We ran a series of events titled 'Death Matters', sessions where people were encouraged to talk about any aspect of death and dying they found interesting and important to them. This document summarizes some of the things we've learned from the experience and offers some advice for how to run similar events in the future.

1. What does a 'Death Matters' event look like?

Most events were 1½-2 hours long, and we found this length about right: it gave people a chance to relax into the session, without overdoing it. We originally intended a session to be about 12 people, though we found with experience that 8-10 individuals gave the best dynamic.

We tried to organise the room in a 'café style' arrangement, with tables to sit around, tea and cake available. This is to encourage people to relax and get away from any suggestion of a classroom or workshop.

We had at least one (and preferably two) people present to facilitate conversation and give the session some structure. They had an outline session plan to use as a guide, but flexibility was very important as people would come with different priorities. So some sessions involved more 'information giving' (e.g. on different practices around the world, or on how to go about planning a funeral). Others spent more time in open-ended conversation. The facilitators made use of a number of devices to stimulate conversation. Of these, a set of five 'Conversation Cards' giving 'icebreaker' questions for people to discuss proved particularly useful.

2. Who comes, and how to encourage them to come along?

Open advertising in public places has relatively poor results, in our experience. Conversations about death can leave people feeling vulnerable, and they will be reluctant to risk them in a strange environment among strangers. We found it more effective to target people who already had a strong connection with Age Concern Birmingham; or who attended a group meeting already at the place where the session would be held. We had a particularly good response with groups of people who already knew each other and were used to interacting together: for example, going to existing day centres or tacking the session on to the end of a regular meeting of an established group.

3. What are people most concerned about?

When asked, we found that the main anxieties people had were not about dying itself, but about the effect that it would have upon their loved ones. In particular, they were concerned that the people close to them might suffer a great burden of care as they were dying; and that after their death these people might be left unsupported or struggling with practical matters. This suggests that sessions of this sort are a good occasion to engage people in practical planning for their own protracted illness, funeral and provision for their loved ones. There are some ethical issues about, for example, inviting one funeral director but not others to explain about the services they offer; but sessions of this type provide a non-threatening environment in which participants can explore practical ways in which they can address their issues of concern.

It is also useful to have to hand information on e.g. local bereavement support organisations, The Samaritans etc.

4. What works, and what doesn't?

It was important to open the sessions clearly, with some ground rules and an introduction to what it was about. In some cases it was useful to have a clear end-point as well, although a number of groups came naturally to a close at around the right time.

In feedback, participants stressed over and over again the importance of practical gestures of hospitality. They noticed that they were entering an environment that was welcoming in practical ways (warm enough, with enough chairs and a thoughtful layout; the provision of tea and home-made cake) and this communicated to them that care had been taken to ensure their welfare. They therefore felt more confident about taking the risk of voicing their concerns regarding this very intimate topic.

Further information

For further information and guidance on how to run an event to talk about death and dying for older people, you may find these useful.

For more information on the project and its lessons, contact:

The full evaluation report (including the session plan and outcomes) is available from Age Concern Birmingham, www.ageconcernbirmingham.org.uk or from Peter Kevern (project evaluator) via email at p.kevern@staffs.ac.uk
Conversation Cards available from Peter Kevern, p.kevern@staffs.ac.uk

More information on café-style events to talk about death and dying:

Kevern, P., & Sanders, J. (2015). 'Death-confident congregations'? Lessons from the GraveTalk Pilot. *Journal of New Writing in Health and Social Care*, 1(2), 21-30, obtainable from

http://www.staffs.ac.uk/academic_depts/health/research/journal_of_new_writing_in_health_and_social_care/journal_of_new_writing_in_health_and_social_care_issue_2.jsp

Resources from the GraveTalk project at

<https://churchofenglandfunerals.org/gravetalk/>

Death Café homepage at www.deathcafe.com

Compassion in Dying (for a range of tools and services):

<http://compassionindying.org.uk/>

Sabatino, C. P. (2014). Advance care planning tools that educate, engage, and empower. *Public Policy & Aging Report*, 24(3), 107-111. Obtainable from

<http://ppar.oxfordjournals.org/content/24/3/107.short>