

# ‘Live Life for Today and Plan for Tomorrow!’

## Abstract

*"Having a good honest discussion about what "I would like" can make the difference between a good death or death in an ambulance on the motorway or waiting on a corridor in an overcrowded hospital."*

Dr Donal Collins GP

## End of Project Report

**AGE** concern  
Gosport



LOTTERY FUNDED

*Let's talk  
about it*



# Project Summary

1.

The idea behind Age Concern Gosport's 'Live Life for Today and Plan for Tomorrow!' came from Gosport Voluntary Action's (GVA's) Chief Officer Nicky Staveley and Gosport's Multi-Speciality Community Provider (MCP) Clinical Lead – Dr Donal Collins, GP. The successful project was awarded National Lottery Funding by the Big Lottery Fund to address the taboo of holding conversations around end of life care, plans and wishes.

The innovative Gosport project was underpinned by evidence such as - nationally 65% of people had not made a will and 45% of people were 'scared'. 1/7 felt that talking about death will make it happen (Comres April 2016). Locally, the Gosport MCP Provider Board felt that saving GP time on practical support matters at the time of death, would enable GP's to provide more clinical support (April 2016).

It was turned into a reality by an experienced, small, but dedicated and enthusiastic project team, including a lead community project and presentations volunteer. Locally it was supported by key organisations (including GVA, Gosport Older Persons Forum, Dying Matters Coalition...).

The team researched and then produced core project documentation and an interactive presentation (which was enhanced during the year using helpful evaluation feedback).

Dying Matters materials were sourced and those in most demand were purchased in bulk. Dying Matters presentations were delivered to 20 community organisations and health related groups.

A publicity campaign was maintained during the year to support awareness raising about the value of holding end of life conversations, particularly during Dying Matters Awareness Week in May 2017 and Gosport's Winter Warmth/55+ INFOFEST event in October 2017.

430 people were engaged with, 190 community volunteer hours (including Age Concern volunteers & trustees) enabled the project to be delivered.



AGE concern  
Gosport

*"One of the big problems the health service faces, is because we don't talk about death or plan for it. Having a good honest discussion about what "I would like" can make the difference between a good death or death in an ambulance on the motorway, or waiting on a corridor in an overcrowded hospital. Raising awareness amongst the public will make a difference. This is an important initiative to which I give my full support."*

Dr Donal Collins GP,  
Multi-Speciality  
Community  
Provider Clinical  
Lead for Gosport.

# The Project's Journey

This is what we said the project would deliver...

"Gosport has areas of deprivation in health, income, education and skills. The project will provide easy access to important information, at venues across the borough. The real difference this project will make, by its very nature, will become evident over a period of time eg when someone subsequently dies who has put things in place re their end of life – as a result of this project."

The project team were recruited



4 interactive outreach events were delivered



20 engaging presentations were given and feedback sought



The presentation and resources were created and sourced



Marketing and PR were strong throughout the project and a wide range of mediums were used, including print, digital, radio and TV.



'Live Life for Today and Plan for Tomorrow! - from Innovation to Reality' abstract was selected for Hospice UK's 2017 Conference 'Leading, Learning and Innovating' – alas our project did not have the £1k to attend. It did illustrate that the innovative local project had received national recognition!

The project was very well supported by partnership organisations and volunteers.

The journey continues....

A new 6 month Pilot Project was proposed, initiated, agreed and started in January 2018 - funded by Southern Health NHS Foundation Trust.

Feedback was sought throughout the project and this was used to improve the sessions. The project was evaluated and an amazing **95%** of attendees said they would recommend the sessions to others. Sample 'follow ups' were undertaken and outcomes recorded. **55%** of those who were followed up had taken some action.



# Dying Matters Key Project Achievements:

430

People were engaged with

95%

Of attendees would recommend the session

190

Volunteer hours were given

1136 people attended presentations and outreach events

The interactive presentations resulted in people noting they would take the following actions:

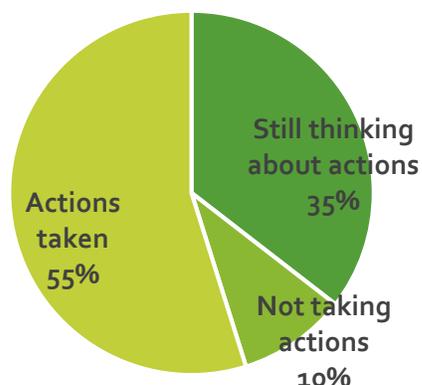
- 64 planned to talk to loved ones about wishes
- 35 planned to set up a care plan
- 30 planned to set up a funeral plan
- 22 planned to sign up for organ donation
- 21 planned to create a will



8.91 was the average rating of usefulness of the sessions, on a scale of 1 to 10.

A sample of 31 attendees were followed up and their actions are detailed below.

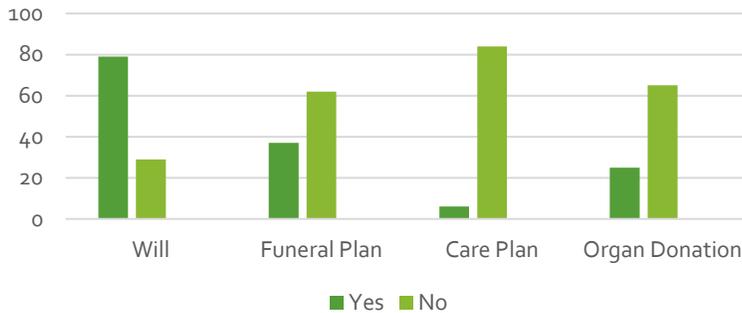
## Attendee Follow Ups



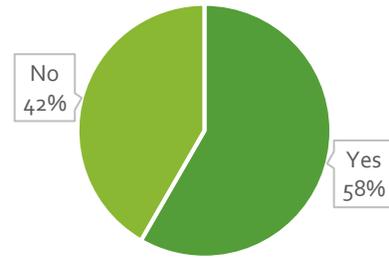
## Actions taken by the 31 attendees who were followed up:

- 5 Wills completed
- 4 Funeral Plans completed
- 1 Care Plan completed
- 8 people had talked to loved ones about wishes
- 4 people had registered for organ donation
- 11 people were still thinking about the actions they planned to take

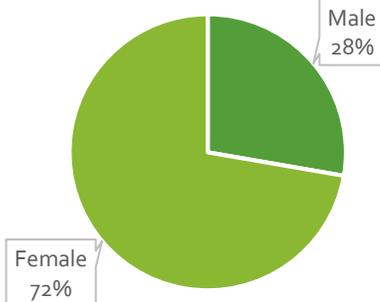
### What did attendees have in place already?



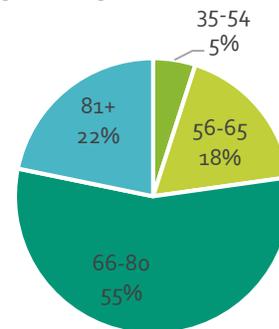
### Had attendees talked to others about their wishes?



### Gender of attendees



### Age range of attendees



*“Lots of helpful information which has been a good reminder that I need to put things in place.”*

*“A well-presented talk both interesting and informative, also made quite entertaining.”*

*“I thought I was organised but this made me realise there is so much more I could do to help my family.”*

## Brenda’s Story

My husband Eddie and I attended the Dying Matters presentation and were grateful for the information we received. We realised one of the most immediate things to do after a loved one has passed away is to arrange the funeral. As both our children live away from home and run their own business, we felt this would be the last thing they would want to face. We have now arranged both our funerals and written down our wishes. We regularly attend church and it was important for both of us that our funerals are held there – all our favourite hymns, readings and music have been chosen and in doing so, taken the strain away from our children at such a difficult time. We regularly recommend to our friends the services Age Concern Gosport offers, as we have found them to be helpful and supportive in filling out difficult forms and providing useful information.



4 Dying Matters Events/Outreach sessions were organised, where 190 people were engaged with.





The project was promoted through printed press, TV, radio, social media, local newsletters and posters/flyers.



Dying Matters - Solent TV 9 May 2017



Dying Matters - BBC Radio Solent 10 Aug 2017

 <https://youtu.be/7APFwQXSZQI>

 <https://youtu.be/EX2kUGM2DaE>

# THE BIG CONVERSATION

Talking about dying won't make it happen

Free Coffee Morning

Saturday 13 May  
10am to 12pm  
Gosport Discovery Centre

Is it time to have 'the Big Conversation' about the wishes of your loved ones? Would you like to receive information so you can:

  
**Make a Will**

  
**Plan your funeral**

  
**Consider organ donation**

  
**Plan for future care**

Come and have a free cuppa, cake and informal chat to find out more...  
No need to book, just turn up

DYING MATTERS AWARENESS WEEK

8 - 14 May 2017  
Book exhibition at Gosport Discovery Centre

The Gosport Globe      Features      Saturday, May 20, 2017      15

## Gosport people want to go travelling before they die

# Top of the bucket list





TALKING POINT: Gosport Mayor of Gosport Councillor Lynn Fildes with participants at the Discovery Centre and, right, organiser




FIDELITY TO THINK ABOUT: Participants in the successful Dying Matters Awareness Week Coffee Morning

The article will help me make my own choices for the remainder of my life. I have been able to talk to my family about my wishes and I feel much more at ease about it. I have been able to talk to my family about my wishes and I feel much more at ease about it. I have been able to talk to my family about my wishes and I feel much more at ease about it.

#YODO you only die once

"It was a relief to finally talk about it"

"I didn't want to add to my family's worries by leaving it all for them to sort out"

# THE BIG CONVERSATION

Talking about dying won't make it happen!

"Finding out what they wanted was such a weight off my mind"

"It was actually really simple once I got going"

Dying Matters

# Big Lottery Fund Support

Big Lottery Fund colleagues were encouraging and supportive throughout the entire 1 year project.

Here are a few of the positive comments from Manuela Scharf (the project's Big Lottery Funding Officer)...

*"Thank you for sending me the publicity materials. I really like the presentation. It's spurred me on to have a closer look into this myself." (2 May 17)*

(After we shared the Dying Matters Project Presentation with Manuela.)

*"The national recognition is a very positive outcome." (23 Aug 17)*

(When our Dying Matters abstract/project was selected as a 'poster' for the National Council for Palliative Care's Conference.)

*"This is great news. Your project has really taken off, I'm glad to hear you can continue. Well done!" (16 Oct 17)*

(After we informed Manuela that Southern Health NHS Foundation Trust had accepted our proposal to fund a Jan-Jun 18 Pilot Project - building upon the project's learning and achievements thus far.)

*"Sounds like you're really well organised for the coming months (I wish all projects were this well planned and executed!) (30 Nov 17)*

(Response to our final 2017 update email explaining that we would collate, produce and share an evaluative End of Project Report in early 2018.)



AGE concern  
Gosport



**NATIONAL  
LOTTERY FUNDED**

# Working in Partnership

In addition to the project's Planning & Review Meetings, its performance and progress were also overseen & proactively supported an enthusiastic small team of Age Concern Gosport Trustees.

Other partner organisations were supportive of the project throughout the year, such as Gosport Older Persons Forum and Gosport Borough Council/the Mayor/s of Gosport.

As an integral part of the project, we aimed to identify and develop a few key working relationships &/or project sponsorship.

This ranged from organisations who very kindly donated towards our outreach event costs eg Ruby Funeralcare and Biscoes solicitors, to those who provided us with help in kind – such as Morrisons, Hutamaki, The Portsmouth News & The Gosport Globe, to those who went 'above & beyond' such as Cooperative Funeralcare Gosport – who provided not only Coop provisions but the use of a free room for the Project Review Meeting and the donation of their 'Open Day' raffle funds to Age Concern Gosport.

*"I was introduced to Angela Gill at a Networking event last year and she very kindly informed me about the Dying Matters project. I was fortunate enough to be able to get involved with one of their events, the Winter Warmth Festival in October last year which I found a very positive experience. I believe the Dying Matters project is a valuable initiative for the local community in raising awareness of all the services available to elderly Clients. I very much hope to be involved in future events with Dying Matters and look forward to supporting them".*



(Alex Brannigan, Chartered Legal Executive, Biscoes, Gosport)

*"As a Funeral Director working within the industry I feel that the Dying Matters Project is invaluable. In this country we have a reluctance to talk about death and dying that is not present in many other countries. The subsequent effect of this is that funeral planning and arrangements are often so very difficult for the families of those who have died as the deceased persons wishes are, at worse, unknown and at best quite vague.*

*I have found that the best experiences families have during this already difficult time is when all concerned have had a good, honest chat about the time that comes to all of us.*

*Dying Matters helps break down the stigma and sense of morbidity that people feel when talking about death. I have had a massive increase in people making enquiries with regard to planning for the future that have quoted the Dying Matters project as the thing that has spurred them on to make those enquiries. All of those who have engaged as a result of that spurring display a palpable sense of relief when matters are put in place.*

*Long may it last! I only wish the project was able to reach more individuals so that we can begin to change this countries fairly Victorian attitudes. Death, after all, is a part of life."*

(Andrew Holt, Funeral Director, Co-operative Funeralcare, Gosport)



# Reflections from our Lead Volunteer

From **Ian Reeves** – Lead Presentation Volunteer, who also supports the project's review and planning.

## What did being the Lead Presentation Volunteer mean to you?

It was interesting to find ways to get people to address, what is a difficult topic and to discuss in the open. I enjoyed trying to find ways to get across the issues and challenge people to think about their future plans. The presentations were always interesting to deliver to the varied audiences we had. I found it rewarding when conversations started and people shared their experiences or views.

## What impact did you observe from the presentations?

Some reticence to discussions on issues, but usually an interest in the range of things people might need to consider in planning their futures. I saw that by the end people were more openly talking about wills, funerals and care plans. I was surprised at the interest in organ donation. I think by the way the team approached the events, we managed to raise awareness in a non-frightening way.

## Anything else you observed Ian?

Obviously, there is more to be done and a recurring theme when people started talking, was that it was often the children who didn't want to talk about dying, funerals and the inevitable future.



**Gosport community news**

# Taking the stigma out of talking about death

The new project is to encourage people to discuss their wishes with loved ones before its too late

TALKING about death and funerals is never easy with loved ones.  
But very often families end up struggling if they have not discussed the wishes of someone who has recently died.  
A new project in Gosport, run by volunteers for Age Concern is hoping to change that.  
Retired management consultant, Ian Reeves, draws on his experience of advice, planning and presentation skills by helping a Big Lottery funded Dying Matters.  
He is aiming to encourage people in Gosport to start conversations, to plan for their future and to ensure that their families and loved ones are aware of their wishes.  
Mr Reeves said: 'I am keen to help in this initiative as I want to put something back into the local community.  
'I believe this is a topic which we all need to address at some stage in our lives, and it's better to do it sooner rather than too late.'  
Mr Reeves is one of a small team of volunteers recruited to the Dying Matters initiative to deliver free talks on a range of sensitive and important end-of-life topics to groups and clubs across Gosport.  
They are aiming to provide people with the information they need to make informed and important choices about the end of their lives.  
It is hoped it will make a real difference for people who take part in the project.  
'I volunteered to be involved in Dying Matters because I wanted to help Age Concern Gosport raise awareness in the community,' said Mr Reeves.  
'I think I can use my work skills to help start that process.'  
There will be a free coffee morning at the Gosport Discovery Centre on the morning of Saturday, May 13, during Dying Matters Awareness Week.  
There will also be an exhibition of books and materials to raise awareness of the benefits of will, care and funeral planning and of talking to families and loved ones about future wishes.  
For information or to book a free group presentation call (023) 9260 4699 or e-mail [dyingmatters@ageconcerngosport.org.uk](mailto:dyingmatters@ageconcerngosport.org.uk).

by ELISE BREWERTON  
*The News*

A photograph of Ian Reeves outdoors, wearing a dark jacket and glasses, standing in a garden with pink flowers in the background.

**DISCUSSION** Ian Reeves is leading a team of volunteers on the Dying Matters project for Age Concern

# Lessons Learnt

## Dying Matters PowerPoint Presentation

- As a result of feedback – we shortened the 'Dying Matters' Presentation
- We enabled people to ask questions during the presentation – to keep it as informal/interactive as possible
- We observed that people were more engaged with the Dying Matters stories - so more 'real life' stories were then told including one on 'IPAD inheritance'!

## Improving the Awareness & Understanding of Dying Matters

- Some organisations weren't always very organised re promoting the Dying Matters presentation - we came up with the idea of a Dying Matters poster that advertised the date/time/venue and also added a few quotes from previous presentations - to highlight and explain more about the Dying Matters project
- The poster was then placed on walls or advertised electronically - to increase awareness of and attendance at, the Dying Matters events

## Communication

- We recognised that the words 'Dying Matters' can make some people uncomfortable, so in 2018 we will pilot 'Your Care in Your Hands – Hospital or Home?' and we'll call the presentations 'talks' - again to reduce any anxiety for potential attendees
- Due to some lower than expected attendance, a more detailed initial engagement was developed, with the inclusion of minimum anticipated attendee numbers
- We will use a hand-held microphone for larger groups of older people in 2018 - as a few older people had difficulty hearing the presentation
- The most popular leaflet was 'My Funeral Wishes' and the second, 'Organ Donation' - once people realised there was no age limit, many were happy to become organ donors

## Savings and Partnership Working

- Throughout the project we began and developed some excellent working relationships and support from key local businesses – who then provided some small scale sponsorship (see Acknowledgements)
- We engaged with organisations such as TT Exchange – resulting in a 50% discount for Microsoft Office
- Savings were also made by asking for discounts from suppliers and by obtaining free PR through local contacts.



# Moving Forward

## Progressing the Pilot Project

- 'Live Life for Today and Plan for Tomorrow!' has made a difference to people's lives and it will have a future impact on GP time &/or hospital admissions
- Recognising the potential and impact of the National Lottery Funded Dying Matters project, a new Pilot Project was proposed, initiated, agreed and started in January 2018, funded by Southern Health NHS Foundation Trust
- The 6 month Project Plan and regular Project Review Meetings are in now place
- Engagement with local doctor's surgeries, patient participation/friends groups and hospitals is underway – particularly in relation to Dying Matters Awareness Week (w/c 14 May 2018)
- The scope of the new Pilot Project has been expanded – it now encompasses Gosport and Fareham
- The new Pilot Project will identify potential synergies eg with GVA's Surgery Signposting Project and by supporting Southern Health NHS Foundation Trust's Frailty Task & Finish & Steering Group
- It will explore engaging with resident's families in 3 identified care/nursing homes

## New Pilot Project Developments

- Based upon evaluation and impact in 2017 and the new remit for 2018, we will pilot an additional new focus of 'Advance Decision Notices'
- There may be demand for assistance completing these – initially we will explore this with the Age Concern Gosport volunteers/service
- We are asking existing 'supporters' to identify what they could do in 2018 - to encourage attendees to take action eg offer discounts, instalments, free advice sessions...
- If this Pilot Project is successful/funded beyond the currently funded period of June 2018, re Gosport's forthcoming 55+ INFO FEST/Winter Warmth event in October 2018, we would want the Age Concern/Dying Matters table to be within the main hall rather than as was in 2017 in the separate music room of Thorngate Hall in October 2018

## Evaluation

- We recognised the need to show the National Lottery Funded impact of 'opening up difficult conversations' and raising awareness – we delivered this with some success
- It will be more challenging to evidence a direct impact for a 6 month pilot project but if, as a result of the Pilot Project, attendees are inspired to put things in place with minimal cost – such as the 'Advance Decision Notice', a longer term impact will ensue for GP's and the local Health Service

## Realising the Project's Future Potential

- If the new Pilot Project can evidence longer term impact and/or savings for primary care, then a discussion will ensue re future funding and/or developing an innovative delivery model - to potentially expand the scope and benefits across the sustainable transformation partnership area
- Any future direction of travel and scope for this engaging Pilot Project will be informed by our future funder's priorities and the learning from the project
- Additional case studies will be identified and attendees who consent to do so, will be followed up and offered additional support as required
- Opportunities to share best practice and learning across the Hampshire Clinical Commissioning Group area and nationally, will be sought and followed up.

# Acknowledgements

Age Concern Gosport would like to give sincere thanks to all who supported the project, including the organisations and individuals listed below, alongside their generous contributions.

Organisation	Contribution
Age Concern Gosport	Support and promotion of the project and volunteer engagement and time
Biscoes	Cost of Equipment Hire for 55+ INFO FEST & Winter Warmth event and attendance at the event
Celebrate Gosport Magazine	Free advertisement during Dying Matters Awareness Week
Citizens Advice Gosport	Free Loan of Projector and promotion of the project
Co-operative Funeralcare Gosport	Tea, Coffee, Sugar & Biscuits / Dying Matters & 55+ INFO FEST & Winter Warmth event and attendance / free meetings room
Dying Matters Coalition (National Council for Palliative Care)	Materials & PR and support for the project
Gosport Borough Council	55+ INFO FEST & Winter Warmth event and overall support for the project
Gosport Choice Magazine	Free advertisement in magazine 55+ INFO FEST & Winter Warmth event
Gosport Discovery Centre	Free use of community area & advertisement of the Dying Matters Awareness Week Exhibition
Gosport Globe	News coverage
Gosport Older Persons' Forum	55+ INFO FEST & Winter Warmth event and support for the project
Gosport Voluntary Action	Loan of Projector/white board/clip boards for 55+ event and overall support for the project
Gosport Wellbeing & Engagement Network	55+ INFO FEST & Winter Warmth event and promotion of the Dying Matters presentations
HMS Sultan	Free advertisement banner on MOD fence 55+ INFO FEST & Winter Warmth event
Huhtamaki	Free provision of coffee cups for the Dying Matters Awareness Week Free Coffee Morning at Gosport Discovery Centre
Morrisons Gosport	Cakes & Biscuits at the above Gosport Discovery Centre event
Older Persons Forum	55+ INFO FEST & Winter Warmth event & promotion of the Dying Matters presentations
Public Guardian Government Department	Free Lasting Power of Attorney forms and their delivery
Richard Conradi	Support and use of the Advanced Personal Information Form
Ruby Funerals	Room Hire for 55+ INFO FEST & Winter Warmth event
Solent Radio	Ian Reeves interview for Dying Matters and 55+ INFO FEST & Winter Warmth event
Solent TV	Angela Gill's TV interview at Gosport Discovery Centre for Dying Matters Awareness Week
The Portsmouth News	News coverage throughout the project
Town Crier	Free Dying Matters advertisement in October magazine