



# Future Matters

Empowering Communities to Plan for  
their Last Years of Life

Year 2 Report

2014/2015



## Table of Contents

<b>INTRODUCTION .....</b>	<b>2</b>
<b>ABOUT FUTURE MATTERS.....</b>	<b>4</b>
<b>SCOPE AND TARGETS.....</b>	<b>5</b>
<b>PROJECT OUTCOMES.....</b>	<b>5</b>
COMMUNITY EVENTS .....	6
ONE TO ONE ADVICE AND SUPPORT .....	8
GP PILOT .....	10
<b>VOLUNTEERS' PERSPECTIVES .....</b>	<b>10</b>
<b>ADDITIONAL OUTCOMES .....</b>	<b>11</b>
REACH .....	11
POETRY.....	12
<b>SUCCESSES, LEARNINGS AND RECOMMENDATIONS .....</b>	<b>12</b>
KEY SUCCESSSES .....	12
KEY LEARNINGS .....	12
KEY RECOMMENDATIONS .....	12
<b>APPENDIX 1: BRIEFINGS TO PROFESSIONALS.....</b>	<b>14</b>
<b>APPENDIX 2: VOLUNTEER POEM .....</b>	<b>15</b>

For further information about **Future Matters** contact:

Debbie Young  
Email: [debbie@gentledusk.org.uk](mailto:debbie@gentledusk.org.uk)  
Phone: 07961 915656

Mireille Hayden  
Email: [info@gentledusk.org.uk](mailto:info@gentledusk.org.uk)  
Phone: 07801 543712

## Introduction

**Future Matters** is a volunteer-led community based solution to raising awareness of end of life care and improving end of life care planning.



Volunteers are trained to become peer educators in planning for the last years of life. They then deliver awareness-raising activities such as workshops, presentations, information stalls and also support clients on a one to one basis to develop and record their plans. They reach out to very diverse communities.

**Future Matters** has been developed over the last 5 years and is a cost effective and successful way of engaging the public, informing them about planning for the last years of life and increasing the uptake of all forms of end of life care planning.

## Background

**Future Matters** answers key requirements for health and social care and addresses both government guidance and patient experience:

- ✓ The latest government guidance (A Review of Choice in End of Life Care, Feb 2015) states that ‘We need to support individuals in making their voices heard, and choices and preferences known’ and advises that ‘each person who has consented to and wishes to specify choices and preferences in their end of life care has these recorded in their individual plan of care’.
- ✓ The Care Act lists as a duty for local authorities to provide information and advice.
- ✓ The National voices survey ‘Every Moment Counts’ (March 2015) provides us with the narrative for the Government guidance above: “I have honest discussions and the chance to plan”; “I have information, in the format I need and that I understand, about all aspects of end of life care, including how to make choices and decisions in advance. This information will include the following potential choices: advance care plan, advance decisions, lasting Power of Attorney, organ and tissue donation”.

We know that the lack of openness around death and dying is hampering the care that professionals can provide, increasing crisis care and unplanned admissions. It is also impeding people having their end of life wishes and choices met, as well as leaving families, carers, loved ones with conflict, guilt and regret.

We also know that 70-80% of all deaths are likely to benefit from planned end of life care (End of Life Care Commissioning Toolkit, October 2012) yet currently only 6% of the population have written preferences and wishes for the care they would want at end of life (Dying Matters ComRes 2014).

Evidence suggests that planning for the last years of life can facilitate the delivery of care more in keeping with patient wishes and increase patient and family satisfaction with care (*BMJ 2013;347:f6064*) as well as improve bereavement for those left behind.

Increasing the uptake of advance care planning depends on raising public awareness of it (Fried et al, 2010) and supporting people to develop their own plans. **Future Matters** addresses both of these issues.

## About Future Matters

The aims of **Future Matters** are to:

- \* Raise awareness of the importance of planning for the last years of life within the community by running workshops, presentations and holding information stalls;
- \* Empower and support people to develop their own end of life care plans including Advance Care Planning; Powers of Attorney; Organ Donation; and
- \* Enable people to voice their choices to their loved ones and those that are responsible for the health and social care.



**In practice** the **Future Matters** project in Islington offers:

- \* **Future Matters** community activities (talks, workshops, events, stalls). These are offered to a variety of organisations from the third sector as well as health and social care settings and include activities delivered in community centres, housing, hospitals etc. Some settings have regular weekly Future Matters activities for e.g. volunteers have been attached to St Luke's community setting and volunteers are also able to offer one to one support in those locations.
- \* A regular **Future Matters** Advice and Planning session (bi-weekly on a Thursday) at Age UK Islington offices, where clients come for a one to one session with a trained volunteer. Clients are offered information and support with all types of planning for the last years of life: advance care planning, powers of attorney, wills, organ and body donation. Most clients take up further support to complete their plans and are offered as many sessions as they need (on average 2-3 sessions of an hour). Some clients may be referred internally to Age UK's free legal and wills advice session and can be signposted to further services if necessary.

## Scope and Targets

**Future Matters** has been commissioned by Islington Clinical Commissioning Group (CCG) since June 2013. The programme is delivered by Gentle Dusk in partnership with Age UK Islington. This report outlines the project's key successes and learnings from Year 2 and sets out recommendations for taking the project forwards into Year 3 (2015/16). It also summarises the activity against the planned targets and highlights a number of additional outcomes that were achieved during Year 2.

### Scope

- A more empowered community
- More open end of life discussions
- More end of life plans, wills and power of attorney's in place
- More people cared for and dying in their preferred place
- Less inappropriate hospital admissions, reduced hospital costs.
- Reduced barriers to end of life conversations with health professionals

### Targets for Year 2 (2014-2015):

- 200 members of the community reached by activities by end of Sept 2014 and 350 by the end of March 2015.
- 6 briefings delivered to professionals by end of Sept 2014 and 12 by the end of March 2015.
- 100 individual consultations held by volunteers by the end of March 2015.
- 50 advance care plans and/or wills, powers of attorney and records of funeral wishes developed.
- The development and piloting of a model of good practice for partnership working with GP practices.

## Project Outcomes

The project has been very successful in reaching out to the community through a diverse range of activities including workshops, events, information stalls and talks. **579 members of the public have been reached** through these activities, significantly exceeding the target. In addition, **over a 100 one to one consultations** have taken place, most of which have been a direct result/referral from the **Future Matters** community activities. **65 end of life care plans** have been put into place with the support of a **Future Matters** volunteer including **29 Advance Care Plans**. See details below.

Many people who have been reached by the project may have developed plans by themselves (as a result of the project) and without the support of a Future Matters volunteer. We have been unable to capture this information but know that the cascade effect is greater than that which we can measure.

## The figures:

### In 12 months - April 2014 to March 2015:

- ✓ **29** Community activities were delivered: 12 workshops, 6 talks/presentations, 2 end of life care events, 9 information stalls.
- ✓ These activities reached **579** members of the public. **62** of which requested a follow up session/information.
- ✓ **105** one to one consultations were delivered.
- ✓ As a result of the one-to-one conversations/consultation with a volunteer **65 plans** were put in place:
  - **29** people completed an Advance Care Plan
  - **2** people wrote draft Advance Decisions to Refuse Treatment
  - **9** people wrote a Will
  - **6** people organised a Power of Attorney
  - **13** people recorded their funeral wishes
  - **5** people registered for full body donation
  - **1** organ donation
- ✓ **12** briefings were delivered to professionals to raise awareness of planning for the last years of life and the **Future Matters** service (See Appendix 1 for details).
- ✓ **Future Matters** 4 day Training programme was delivered to a further **7** trainees to ensure continuation of a pool of active volunteers.

## Community Events

Five hundred and seventy-nine members of the public were reached through community awareness raising activities. These activities were presentations to large audiences, workshops to medium or small groups and information stalls- see table 1 below for details. The volunteers use a variety of interactive activities and tools to support the delivery of their events including short films, presentations, poems, quizzes, games and leaflets.

<b>Table 1: Community events delivered by Future Matters volunteers. April 14 to March 15</b>					
	<b>Event Name</b>	<b>Activity</b>	<b>Date</b>	<b>No. attended</b>	<b>Follow ups</b>
1	St Lukes Community Centre (Support Grp for Older Carers)	Workshop	07.04.14	5	4
2	Barnsbury Open Day	Information stall	09.04.14	50	0
3	Alsen Day Centre	Workshop	10.04.14	10	0
4	73 Milldmay (Extra Care Supported Housing)	Workshop	24.04.14	14	4
5	20-26 Mildmay (Extra Care Supported Housing)	Workshop	29.04.14	13	1
6	Brightwell Court (Sheltered Housing, Circle Support)	Workshop	07.05.14	12	3
7	Claremont	Workshop	12.05.14	4	1
8	Claremont	Workshop	13.05.14	4	1
9	Drovers Film Club	Workshop	13.05.14	16	0
10	Whittington Hospital Atrium	Information Stall	13.05.14	61	6
11	Islington CCG Event	Information Stall	14.05.14	25	2
12	Last Words poetry evening at Waterstones	Event	15.05.14	32	2
13	Peel Institute Film Club	Workshop	16.05.14	15	0
14	Islington Carers event	Information Stall	09.06.14	30	0
15	St Lukes Community Centre	Presentation	19.06.14	21	5
16	Cope House (Circle Support)	Information Stall	19.06.14	50	3
17	Pulmonary Rehab group – Whittington Hospital (1)	Talk	27.06.14	11	2
18	New Park Day Centre	Workshop	23.09.14	20	2
19	Foxham Road (Sheltered Housing, Circle Support)	Workshop	24.09.14	10	1
20	Pulmonary Rehab group – Whittington Hospital (2)	Talk	25.09.14	5	0
21	Duvall House (Sheltered Housing, Circle Support)	Information Stall	25.09.14	42	5
22	Voices for Change, St Joseph's Hospital	Talk	02.10.14	8	1
23	Duvall House (Sheltered Housing, Circle Support)	Workshop	13.11.14	8	0
24	Pulmonary Rehab group – Whittington Hospital (3)	Talk	20.11.14	8	0
25	UCLH Atrium	Information Stall	25.11.14	56	9
26	St Lukes Community Centre, EC1V 8AJ	Information Stall	25.11.14	10	0
27	Age UK Islington Life Planning Event	Event	03.02.15	28	5
28	St Lukes Community Centre, EC1V 8AJ	Information Stall	06.02.15	6	1
29	Pulmonary Rehab group – Whittington Hospital (4)	Talk	<b>06.02.15</b>	6	6
			<b>TOTAL</b>	<b>579</b>	<b>62</b>

- **Note: Community Activities delivered during Dying Matters Week**

## One to One Advice and Support



One hundred and five clients were reached via one-to-one conversations held by the volunteers. The majority of clients (48%) attended the Future Matters Advice and Support sessions after attending a Future Matters community event. This demonstrates the importance of raising awareness of planning for the last years of life within the community and the positive impact that this has on the audience. Fifteen per cent of clients were referred to the service internally by Age UK Islington following on from an Advice and Information session and 11% were self-referrals. GP and health professionals only accounted for 4.8% of referrals.

### Topics discussed during the one-to-one conversations

Future Matters volunteers discuss with clients all appropriate end of life care planning topics and cover a broad range of issues in every consultation. Advance care planning (ACP) is discussed in almost every session (94.3%), and the topics most often discussed are wills (65.7%), discussing ACP with family, friends (63.8%) and GP/health professionals (61%) as well as funeral wishes (62.9%) and powers of attorney (57.1%).

	<b>Response Percent</b>
Advance Care Planning (ACP)	94.3%
Discussing ACP or their wishes with family/friends	63.8%
Discussing ACP or their wishes with their GP/health professionals	61.0%
Wills	65.7%
Powers of Attorney	57.1%
Funeral Wishes	62.9%
Organ Donation	43.8%
Full Body Donation	8.6%
Other	10.5%

### Plans completed by the clients as a result of volunteer support

Sixty-five end of life plans were put in place as a result of a **Future Matters** consultation. Table 3 provides a summary of the plans that were completed by clients as a direct result of support from a volunteer.



	<b>Response Count</b>
Completed an Advance Care Plan (ACP)	29
Discussed their ACP or their wishes with family/friends	15
Discuss their ACP or wishes with their GP	7
Written a Will	9
Organised a Power of Attorney	6
Recorded funeral wishes	13
Registered as an Organ Donor	1
Registered as Full Body Donor	5
Written draft Advance Decisions to Refuse Treatment	2

Many clients who have been reached by the project may have completed plans without the help of a volunteer. For example, advance care planning templates were given out during workshops and at one-to-one conversations and many clients were happy to complete the form by themselves. Advance care planning templates are also downloaded directly from both Age UK Islington and Gentle Dusk websites. We have been unable to capture these additional outcomes.

#### **Profile of the clients reached via one-to-one conversations**

Monitoring of service users shows that the Future Matters sessions are suitable and accessible to both women and men. Out of the 105 clients 58% were female and 42% were male. The majority of the clients are 66 and over (80%) – see table 2 for breakdown.

	<b>Response Percent</b>
18-35	1
36-50	2.9
51-65	16.2
66-75	40
Over 75	40

**Future Matters** is appropriate and accessible to diverse ethnicities and the ethnicities of individuals accessing one to one consultations closely reflect the local ethnicity data. Indeed in Islington according to the last census: 57% of residents are white British, 13% are black/African/Caribbean/Black British, 9% are Asian, 6% are mixed ethnic group and 3% are other ethnic group. Table 3 below shows the ethnicity of clients accessing one to one advice and support.

Table 5: Ethnicity of Clients	
	Response Percent
Asian/Asian British - Indian	2.9%
Asian/Asian British - Other	1.0%
Black/Black British - African	3.9%
Black/Black British - Caribbean	7.8%
Chinese	1.0%
Mixed - Other	2.9%
White - British	57.3%
White - Irish	8.7%
White - Other	7.8%
Other	6.8%

## GP Pilot

The development and piloting of a model of referral and support for patients within GP practices was undertaken. A **Future Matters** volunteer was assigned/attached to an Islington Primary Care Centre to support practice patients in planning for the last years of life. The support was advertised in a number of ways to both patients and practice GPs: Posters and leaflets were designed and made available within the practice; information was developed for the practice digital screen; meetings were held for GPs and practice staff and a partnership agreement was developed between the project and the practice. However, in 6 months only 1 patient was referred for support. There are a number of barriers to this work in GP practices: the workload is considerable and GPs find it difficult to bring up the issue of end of life planning. Their consultations are fast paced and focus on problem solving and therefore the time and opportunities are not always readily available to convince a patient of the need to plan of the last years of life.

In addition, the volume of patients has to be considerable to generate referrals. A possible way forward would be to generate referrals from a number of practices. In terms of cost effectiveness, volunteer community activities are more successful in generating referrals.

## Volunteers' perspectives



The success of the project is greatly due to the hard work and exceptional quality of volunteers. They bring a rich variety of skills to the project and high levels of enthusiasm.



A [Future Matters](#) volunteer tells her story below:

**Perspective of a Future Matters Volunteer**  
**Written by Sarah Ninian**

I first heard of Future Matters through volunteering in the Enquiries Office at Manor Gardens. It immediately appealed to me because I was constantly meeting clients who had no plans for their future years, and who were daunted and scared by the prospect of making them. To be a trained Future Matters volunteer was a way of learning how to support these clients and also a way of supporting a very worthwhile project.

From a selfish point of view, there were advantages for me too! It would be another string to my bow, and would be a great learning experience for me, giving me the chance to learn about the various aspects (legal, care and so on) of coping with later life. It would also give me the chance to do things that I did not do in enquiries, such as having the opportunity to learn about having one-to-one sessions with clients. It would also give me the chance of working with different people in a different team. So there were many advantages for me – mainly that it was something new and worthwhile.

I enrolled on the training course in September 2014. The course was 4 days, with an optional 5<sup>th</sup> for those interested in being trained as a one to one volunteer. The course was fascinating, each day focussing on a different aspect of helping people plan their future lives. The facilitators, Mireille and Debbie were professional and totally on top of their subject yet made it fun. They worked exceptionally well together, and we also had outside companies and individuals coming in to speak to us.

As a trained volunteer, I have taken part in different types of events – which is another advantage, you can pick and choose what you want to be involved in, and how much time you want to donate to the project. The support after the training is huge, and so is the satisfaction in being part of this worthwhile team.

I can thoroughly recommend becoming a Future Matters volunteer – even if you have only a small time to give, this will be so appreciated.

A volunteer's provides an account of a [Future Matters](#) one-to-one session:

**A Volunteers Account**

**Written by Rick Taylor**

Many clients that we see for Future Matters (FM) are relatively straight-forward and able to complete their Advance Care Plan (ACP) in two or three sessions. With a certain amount of jiggling of dates, they are usually able to complete all sessions with the same advisor.

However, this is not always the case. Sometimes it is necessary to have more than three sessions due to various difficulties that the client might experience.

Mr C, was keen to complete the full FM program, including ACP, Funeral Planning, Will Making and Full Body Donation. He was clear about what he wanted from the start and wished to complete The Full Body Donation application immediately.

Mr C explained that he was suffering from memory issues and that he had consulted his GP about this. Mr C wished to complete the Body Donation forms for the London Clinic in his first session and took them away to have signed, witnessed and sent off. He also

completed part of his ACP. A new appointment was made for Mr C to complete his ACP and make decisions about funeral planning and his will. This next meeting was several weeks away as the client expressed a wish to see the same advisor.

Due to his memory issues, he missed a number of appointments and forgot and lost some of the documents. However, the advisors were able to transfer the various notes and partially completed information onto an electronic version of the ACP form taking the client carefully through each section.

The client said on leaving that he felt very happy and relieved to have now completed his entire end of life plan.

This case study demonstrates that sometimes it is worth persisting with a client even if they need more time to complete the plan. Also, all FM advisors are trained to the same high standard so switching from one advisor to another, is not necessarily an issue.

This represents a successful outcome both for the client as well as for the FM team, despite the difficulties.

## Additional outcomes

### Reach

Information about **Future Matters** is available throughout a number of media and fora to ensure the service is advertised as widely as possible. This also serves as further awareness raising for planning for the last years of life:

- An article about Future Matters & Dying Matters week featured in Islington Gazette May 2014:[http://www.islingtongazette.co.uk/news/waterstones\\_in\\_islington\\_hosts\\_death\\_themed\\_poetry\\_day\\_1\\_3610453](http://www.islingtongazette.co.uk/news/waterstones_in_islington_hosts_death_themed_poetry_day_1_3610453). The Islington Gazette reaches 21,000 via their print and 13,200 via their website.
- A service leaflet and an A5 flier were updated and 1,000 copies of the leaflet and 5,000 copies of the flier were printed for distribution.
- Information about Future Matters was also updated on the Age UK Islington webpage as well as the Gentle Dusk website. Both sites have made the Advance Care Plan easily downloadable.
- Information about Future Matters was shared with the CCG for the GP e-newsletter in May and June 2014.
- Facebook and Twitter are also being used to promote the project and information about End of life care. To date we have 35 facebook and 244 twitter followers.

The project as a whole has also received a lot of interest on a national level with Dying Matters covering our Dying Matters week poetry event in their newsletter in August 2014 (reaching 17,000 members) <http://dyingmatters.org/sites/default/files/SummerNewsletter2014.pdf>;

A story about Gentle Dusk and the Future Matters project was also featured on the Dying Matters blog: <http://dyingmatters.org/blog/FutureMatters>; and a **Future Matters** volunteer presented the project at the national Dying Matters Week launch conference in January 2015.

## Poetry

Future Matters volunteer Rick Taylor entered the Dying Matters 2014 creative writing competition. His poem, one of 500 hundred entries, was Highly Commended. [A Final Journey](#) by Rick Taylor can be found in Appendix 2.

## Successes, learnings and recommendations

### Key Successes

- ✓ **Future Matters** has been very successful in reaching out to local communities and raising awareness of the need to plan for the last years of life. Impacting on 579 members of the public through workshops, talks and stalls is a significant success.
- ✓ The fact that community activities generate the greatest amount of referrals (48%) to the one to one support/consultations is a testament to their success.
- ✓ Achieving 105 consultations resulting in 65 end of life care plans put in place including 29 Advance Care Plans is another great accomplishment.
- ✓ Through effective publicity, briefings and trainings to professionals, as well as word of mouth of its success, **Future Matters** is known to many health professionals and members of the public in Islington.
- ✓ Both the quality and commitment of volunteers and the partnership between Gentle Dusk and Age UK Islington have significantly contributed to the success of **Future Matters**.
- ✓ Both organisations show high levels of dedication and commitment to the work. This has enabled the targets to be exceeded this year by inputting time and resources over and above what has been commissioned.

### Key Learnings

Whilst the Future Matters service has been well received by health and social care professionals it has been a challenging task to embed referrals to the service in GP practices and professional teams. We have underestimated the resources required to achieve increased reach and embed referral processes for this particular project.

Future Matters outcomes have been achieved through partnership, cross referrals with other services and outreach work from Gentle Dusk and Age UK Islington. The project benefits from the support of a strong core volunteer team. More reach and client outcomes could be achieved in the future.

The success of the Future Matters service has increased client demand for volunteer supervision, mentoring, support and casework. We are ensuring that we continue to offer a useful and responsive service and recognise that future development is limited by the current level of resources.

## Key Recommendations

### Recommendations for Future Matters

1. Continue to target the over 60s age group and to focus on encouraging people to plan early for their last years of life.
2. Continue to deliver a range of interactive awareness raising activities within the borough and encourage attendees to book for one-to-one sessions to develop plans.
3. Raise awareness of **Future Matters** amongst health and social care professionals.
4. Put a procedure in place to link completed Advance Care Plans back to GPs to ensure ACPs are recorded on the patient's record.
5. Continue to provide responsive service in line with current level of resources.

### Recommendations for Islington Clinical Commissioning Group (CCG)

1. Support **Future Matters** to promote the project amongst other key services where clients would benefit from early planning e.g. social services.
2. Raise awareness of **Future Matters** amongst GP practices so as to increase the number of referrals e.g. articles in the GP e-bulletin, promotion by Macmillan palliative care GP facilitator and information on the GP digital information screens.
3. Review funding for **Future Matters** to enable continued responsiveness to local community.

## Appendix 1: Briefings to professionals

12 briefings were delivered to professionals to raise awareness of planning for the last years of life and the **Future Matters** service.

<b>Team/ Department</b>	<b>Date</b>	<b>Numbers</b>
Social Work Team (South)	02.04.14	20
Mildmay Extra Support Scheme	02.04.14	8
UCLH Discharge Strategy Meeting	08.07.14	10
UCLH Transforming EoLC Services Team	16.07.14	3
Whittington Hospital Community Respiratory team	05.08.14	12
Whittington/UCLH Social Work Teams	10.09.14	20
Voices for Change Group	02.10.14	8
Centre 404 (Learning Difficulties)	14.11.14	2
Peabody Trust	24.11.14	2
Elfrieda Society Learning Difficulties	24.11.14	1
UCLH Frailty Group Meeting	09.12.14	10
Family Mosaic Housing Association	09.12.14	2

## Appendix 2: Volunteer Poem

### A Final Journey by Rick Taylor

It is autumn, which is as it should be.  
As the sap withdraws to mark the winter –  
soul wasting winds and spirit sapping cold  
and water crystallized to frosted glass.  
All life prepares for what is to come.  
For me, this autumn is no ordinary season –  
the ones that come and go, along with the years –  
like birthdays or Christmas.  
For this I know is to be my last.  
How do I know this?  
I was led silently into a white-faced room  
and he told me so, quite plain.  
Well, after all the stuff about metastasized tumors  
and treatment plans, he told me when I asked.  
*'Of course we can never be sure, but I would be surprised  
if you made it through the year.'*  
And so it is, as I watch the swallows and other birds of  
myriad hue gather for migration, knowing that for some,  
this will be their final journey,  
as the very old, the weak, the young, succumb  
to the miles stretching out beyond.  
It is with an aching heart but an intense perception  
that I tick off the ever-growing list of lasts.  
And then I wonder why it is,  
I have never really seen these things before –  
not in the way I see them now.  
The wind eddying the leaves and the evening light  
glancing off the surface of the water  
as the swallows rise in a dark swarm  
and head out across the deadening sky:  
Too late to understand mindfulness  
and how it is that we should live each day  
as though it were our last;  
Too late for the bad feelings and negative thoughts;  
Too late for the many things left undone,  
or done, and wished undone.  
Now just the creeping pain and the flickering light  
as the world dims to the unknown blackness of eternal night.

Highly commended; Dying Matters Creative writing competition 2014