



Future Matters

Empowering Communities to Plan for
their Last Years of Life



Year 1 Report
2013/2014

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For further information about the Future Matters project contact:

Debbie Young
Future Matters Programme Manager, Gentle Dusk
Email:Debbie@gentledusk.org.uk
Phone: 07961 915656

Introduction

Death is a taboo. We all know that the reluctance to talk openly about dying and death is a significant barrier to people receiving the type of end of life care they need and want, leading to unnecessary and unwanted admissions to hospitals in the last days of life and leaving families with insurmountable difficulties. 70% of people say they would wish to die at home. In Islington 23% of people achieve this. So how do we change society's approach to such a difficult subject? By training members of the public to become Future Matters volunteers, awareness about planning for the last years of life can be cascaded to a wide range of communities and community organisations and will help break the silence and improve care. Residents will be enabled and empowered to discuss and plan for their future care and support and thus have more control over the end of their life.

About the Future Matters Project

In June 2013, Islington Clinical Commissioning Group (CCG) commissioned Gentle Dusk to deliver the Future Matters programme in Islington over a 2 year period (2013-2015). Gentle Dusk is working in partnership with Age UK Islington to ensure delivery of a successful project that reaches as many diverse communities as possible.

The aims of the Future Matters project are to:

- raise awareness of the importance of planning for the last years of life within the community by running workshops and holding information stalls;
- empower and support people to develop their plans including an Advance Care Plan;
- enable people to voice their choices to their loved ones and those that are responsible for the health and social care.

Our outcomes for Year 1 were:

- Outcome 1 - 15 volunteers recruited to become Future Matters volunteers by September 2013 and 25 recruited by January 2014;
- Outcome 2 - 15 Future Matters volunteers trained to Level 1 (of the Future Matters: Planning for the Last Years of Life training programme) by October 2013 and 25 by February 2014;
- Outcome 3 - 10 volunteers trained to Level 2 (of the Future Matters: Planning for the Last Years of Life training programme) by February 2014;
- Outcome 4 - 10 GP practices/care homes to have a Future Matters volunteers attached to their service by March 2014 so they can raise awareness with patients and care home residents and support, where appropriate, the completion of advance care plans;
- Outcome 5 - 150 Last Years of Life Planning conversations held by the Future Matters volunteers by end of December 2013 and 400 by the end of March 2014;
- To count the number of advance care plans, Wills and funeral plans developed.

This report outlines the projects key successes and learnings for Year 1 and sets out recommendations for taking the project forwards into Year 2 (2014/15). It also summaries the activity against the outcomes above and highlights a number of additional outcomes that were achieved during Year 1.

Section One: Summary of Project Outcomes

- **29** Future Matters volunteers were recruited by January 2014.
- **28** Future Matters volunteers completed the Level 1 training by February 2014. Level 1 training equips the volunteers with the knowledge and skills to raise awareness of the importance of planning for the last years of life within the community and to run workshops and hold information stalls in the community.
- **22** Future Matters volunteers completed the Level 2 training by February 2014. Level 2 training equips the volunteers with the knowledge and skills to be attached to a GP practice, care home or other appropriate setting so they can raise awareness of with patients and care home residents and support, where appropriate, the completion of advance care planning.
- **98** community organisations were contacted by Age UK Islington and were provided with information about Future Matters and/or asked if they would like Future Matters to deliver an activity for their clients.
- **17** community events were delivered by the Future Matters volunteers between October 2013 and March 2014.
- **262** members of the public were reached by these community events.
- **10** (3 GP practices, 4 Care Homes and an Extra Care Scheme) services had a Future Matters volunteers attached to their service by March 2014.
- Age UK Islington set up an internal referral system and one-to-one fortnightly Future Matters appointments as part of their Information and Advice Service.
- **158** people were reached via one-to-one conversations.
- As a result of the one-to-one conversations/consultation with a volunteer:
 - **12** people completed an Advance Care Plan
 - **11** people wrote a Will
 - **9** people organised a Power of Attorney
 - **10** people recorded their funeral wishes
 - **5** people registered as an organ donor

NOTES: 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 unable to capture this information.

It is also important to note that the individual appointments at the 10 settings only began in November 2013 so most of this activity has been achieved over a 5-month period.

- **7** presentations were made to organisations/services in Islington by the Future Matters staff team.
- A Future Matters Advance Care Planning document was developed.

Section Two: Key Successes & Learnings

Key Successes

1. **The partnership between Age UK Islington and Gentle Dusk has significantly contributed to the success of the project.** Age UK Islington has expertise in recruiting and managing volunteers from a range of backgrounds and has day-to day contact with significant numbers of older people in the borough. They also have contact with a vast network of community organisations/services. Gentle Dusk has brought expertise in the field of end of life care and planning for the last years of life, has been able to deliver an in-depth and engaging training programme for volunteers and has a significant network of contacts both locally, pan-London and nationally with which to share resources and learning.
2. **The commitment, enthusiasm and skills of the Future Matters volunteers have enabled this relatively new and innovative project to develop and grow and to outreach into the community.** The volunteers have influenced the direction and growth of the project by readily giving their views and providing suggestions on ways to take the project forward. They have also fed back from their community events and one-to-ones about what works and areas that need developing. Some volunteers have contributed significantly to the development of new resources such as developing short films and designing publicity materials and other volunteers have outreached into their local communities engaging the public in conversations and introducing the project to new community groups.

Perspective of the Future Matters Project Co-ordinator

Written by Caroline Sullivan, Co-ordinator for the Future Matters project

As a coordinator on the Future Matters project I have been most struck by the individual skills and qualities the volunteers have brought to the project; and how the project has evolved and grown as a direct result of these.

Encouraging Future Matters volunteers to not only use their existing skills, but to work collaboratively with other volunteers to enhance *other* skills has been a particular strength of the way in which the project has worked. For example, one of the volunteers is an experienced facilitator who was able to design a workshop; which was in turn able to be used as a template for other volunteers designing community events. In this way volunteers who had initially expressed an interest in doing primarily work on information stalls, have been able to support community presentations and take an active role in planning meetings, with a view to participating more widely in future presentations.

As volunteers have felt empowered, this has in turn led to them developing contacts and suggesting ideas, leads, and systems of working; which has helped us create networks and systems which are reflective of the volunteers themselves.

3. **Community awareness raising events that led to people booking a one-to-one appointment.** The community awareness raising workshops have been well received amongst the general public. The volunteers have delivered the information using a range of interactive activities which has kept participants engaged and interested. We have found that after we have delivered a workshop many attendees feel motivated to put plans in place and to sign up for a one-to-one appointment with a volunteer. This approach needs to be built upon as we move into Year 2.
4. **The one-to-one consultations managed through Age UK Islington.** The majority of the booked one-to-one consultations have taken place via Age UK Islington's Information and Advice service. The clients have had between 1 - 3 one-hour sessions and therefore have had a significant amount of time and support from volunteers to discuss their wishes and to put their plans in place.
5. **When planning for the last years of life begins early.** It has become apparent during the course of the year that the Future Matters project works most effectively when we support people to develop their end of life care plans early while they are still relatively healthy and before a terminal diagnosis or the onset of dementia. We have found in our community workshops that older people are usually relatively open to talking about death and dying, if given the opportunity, and often feel reassured and relieved once they have put their plans in place.

Key Learnings

1. Attaching volunteers to organisations

Attaching volunteers to organisations i.e. GP practices and care homes is more time-consuming than expected. An agreement/contract was developed to outline how the volunteer would work within that particular organisation and how the volunteer would be supported. Between 1-2 meetings were then held with the organisation to agree and establish these working arrangements. Sometimes further meetings were required to iron out difficulties.

The success of this model depends on the organisation making and supporting referrals to the attached volunteers. To date the number of referrals have been low, and in some cases there haven't been any, which means there is very poor return on our initial investment.

- a. **Attaching volunteers to GP practices.** Given the time it takes to set up a volunteer with an organisation (as outlined above) it is disappointing that the number of referrals from GPs has been low. It is unclear exactly why this is the case but it is assumed that as a GP still needs to have a conversation with a patient about planning for the last years of life in order to refer a patient to the volunteer, these conversations may not be happening. Also GPs have a very short time within a consultation to raise the issue, if it is not the issue that the patient is presenting with at that time. Information has also been displayed in the GP practice waiting areas so patients can self-refer but this appears not to be happening either.

b. Attaching volunteers to Care Homes. Volunteers were attached to 4 care homes in the borough. However, the volunteers found this setting very difficult to volunteer in and felt unequipped to support residents with their planning for last years of life. There were a number of reasons for this;

- **The high numbers of residents with dementia.** This made it very difficult for the volunteers to help residents with their planning as few had capacity. The focus of Future Matters has always been to start planning early and therefore the volunteers had not received training about completing advance care plans with those with early dementia or completing plans with relatives. In 3 care homes the volunteers gave presentations about their role at relatives meetings but very few relatives came forward for support to help develop plans for the relatives “in the best interests”. The volunteers were very clear that in this setting the planning was taking place too late.
- **Tokenistic advance care plans** were in place. Many of the residents did in fact have some kind of end of life care/advance care plan in place and some level of discussion has already taken place with residents by the staff. However, the quality and depth of these plans varied amongst the care homes and there was some evidence of “cutting and pasting” between residents plans. In addition, as the care home staff had had some level of prior end of life care conversation with the resident the volunteers found it difficult to re-visit these conversations as the residents felt this had already been done!

Many of the care home staff have long-term relationships with the residents and know them well. For this reason it is felt that, with training in advance care planning, the staff would be able to complete more comprehensive plans for the residents, working alongside the relatives who they already have a relationship with.

- **Volunteer vs Advocate role.** Sometimes the residents would tell the volunteers about aspects of their care that they were unhappy with or sometimes the volunteers would see things that they were not comfortable with i.e. an unanswered buzzer. The volunteers then felt a need to advocate on behalf the resident but were aware that this was outside the boundaries of their role of a Future Matters volunteer.

Key Learning:

The success of this model is dependent on the organisation that the volunteer is attached to;

- the organisation lead member of staff needs to be fully invested in the programme, and be able to cascade that to its staff; and
- the organisation’s client group need to have mental capacity.

Action:

We are looking at working closely with a GP Practice that is very supportive and invested in this area of work, and using the findings from this work as a model for best practice.

Section Three: Recommendations for Year 2

Recommendations for the Future Matters Project

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 social work teams, district nursing, GP Practices and relevant services within Whittington and University College Hospitals by offering briefing sessions. Encourage services to refer clients directly to Age UK Islington for a one-to-one consultation.
4. Work closely with Hanley Primary Care Centre to pilot how the Future Matters project can link with GP Practices. The findings from this work will be used as a model for best practice and shared with other GP practices.

Recommendations for Islington Clinical Commissioning Group (CCG)

1. **Train professionals about planning for the last years of life and advance care planning.** There has been a great deal of interest about Future Matters amongst professionals. This has manifested itself through the number of requests we have received to talk to staff groups within different services and organisations. There is a need for professionals and care workers to receive training about planning for the last years of life particularly advance care planning and how to begin conversations about death, dying and end of life care. Training could focus on Social Workers, those working in supported housing and care homes and those working with people with learning difficulties.
2. **Raise awareness of Future Matters amongst GP practices so as to increase the number of referrals.** This could include articles in the GP e-bulletin, information about the project distributed at GP training events, promotion by Dr Patrick McDaid during practice visits and information on the GP digital information screens.
3. **Support Future Matters to promote the project amongst other key services where clients would benefit from early planning** e.g. social services, supported housing and organisations that support those with learning difficulties.

Section Four: Detailed Project Outcomes

1. Marketing

To ensure that the Future Matters project was advertised successfully to both the general public and professionals a range of marketing materials were developed (e.g. leaflets, fliers and posters) throughout the year. These were distributed widely within the local community using Age UK Islington's extensive networks.

Articles were also written for local community magazines (e.g. Islington Life) and e-bulletins (e.g. Health Watch Islington and GPs). Regular news feeds were also made via Facebook and Twitter. See Table 1 for a breakdown of all publicity materials developed and articles written during Year 1.

| Table 1: Publicity materials developed and articles written | | |
|--|------------------------|--|
| Publicity material | Date developed | Circulation (where appropriate) |
| Future Matters Publicity Leaflet | June 2013 | 1,000 distributed |
| Articles in GP Bulletin | June and December 2013 | Circulated to all GPs and Practice Managers |
| Future Matters Banner | November 2013 | Displayed at all community awareness raising events |
| Future Matters A5 leaflets | December 2013 | 5,000 - in distribution to individuals at community events, through Enablement service, GP surgeries |
| Article in Islington Life | December 2013 | Distributed to 93,600 households |
| Future Matters posters | January 2014 | 500 distributed |
| GP Digital Information screens | February 2014 | Future Matters information displayed on screens in the 12 GP practices that have screens |
| Article in Health Watch Islington e-bulletin | March 2014 | Health Watch website news page http://www.healthwatchislington.co.uk/news |
| Facebook and Twitter | On-going | Regular newsfeeds |

2. Recruitment of volunteers

Outcome 1:

Planned Outcome - 15 volunteers recruited by Sept 13 & 25 recruited by January 14

Achieved Outcome - 14 volunteers recruited by Sept 13 & 29 recruited by January 14

The Future Matters volunteer opportunity was advertised within the local community, on the Guardian and HereTo websites and via Twitter and Facebook. Recruitment fliers were printed and distributed in local libraries and other community settings.

Five information days were held for interested volunteers so they could learn more about the project and the commitment required.

The volunteers recruited came from a wide range of different backgrounds as shown in Tables 2 & 3.

Table 2: Demographics of the 14 volunteers recruited to be Future Matters Volunteers (Sept 13)

| Age and Gender | Ethnicity | Religion | Sexual Orientation |
|----------------|----------------------------|-----------------------|-----------------------|
| 36–50 = 4 | White British = 9 | Christian = 1 | Heterosexual = 3 |
| 51–65 = 8 | Other White background = 4 | None = 2 | LGB = 0 |
| Over 65 = 2 | African = 1 | Judaism = 1 | Did not disclose = 11 |
| Male = 3 | | Did not disclose = 10 | |
| Female = 11 | | | |

Table 3: Demographics of the 15 volunteers (& 2ACP Nurses) recruited to be Future Matters Volunteers (Jan 14)

| Age and Gender | Ethnicity | Religion | Sexual Orientation | Disability | Employment |
|----------------|----------------------------|---------------|----------------------|------------|---------------------------------|
| 36–50 = 7 | White British = 10 | Christian = 7 | Heterosexual = 14 | Yes = 4 | Professional/senior manager = 9 |
| 51–65 = 6 | Caribbean = 3 | None = 7 | LGB = 1 | No = 13 | Skilled/manual workers = 5 |
| Over 65 = 4 | Other White background = 2 | Hinduism = 1 | Did not disclose = 2 | | Other = 2 |
| Male = 3 | Indian = 1 | Buddhist = 1 | | | Did not disclose = 1 |
| Female = 14 | Did not disclose = 1 | Other = 1 | | | |

3. Training of the Future Matters Volunteers

Outcomes 2 and 3:

Planned Outcome - 15 Future Matters volunteers trained to Level 1 (of the Future Matters: Planning for the Last Years of Life training programme) by Oct 2013 and 25 by Feb 2014;

Achieved Outcome - 13 Future Matters volunteers trained to Level 1 by Oct 2013 and 28 trained by Feb 2014

Planned Outcome - 10 volunteers trained to Level 2 (of the Future Matters: Planning for the Last Years of Life training programme) by February 2014.

Achieved Outcome - 22 volunteers trained to Level 2 by Feb 2014

All Future Matters volunteers were required to complete the Level 1 training programme which consists of 7 modules delivered over 3.5 days. The Level 1 training equips the volunteers with the knowledge and skills to raise awareness of the importance of planning for the last years of life within the community and to run workshops and hold information stalls in the community. Future Matters volunteers that were interested in supporting people on a one-to-one basis to develop their plans (including an Advance Care Plan) and who were assessed by the trainers to have the appropriate skills and qualities (see page 14) were required to attend the Level 2 training which was an additional 1 day of training. This day equips the volunteers with the knowledge and skills to be attached to a GP practice, care home or other appropriate setting.

A summary of the Future Matters Planning for the Last Years of Life Training programme is outlined in the box overleaf

.Future Matters Planning for the Last Years of Life Training Programme

Level 1

Module 1 : An introduction to planning for the last years of life and the Future Matters role

Module 2: Putting your house in order, part 1 (Wills and Powers of Attorney)

Module 3: Introduction to Advance care planning

Module 4: Putting your house in order, part 2 (Local services and funerals, burials & cremations)

Module 5: Loss and bereavement

Module 6: Future Matters volunteer skills

Module 7: Putting it into practice: Community activities

Level 2

Module 8: Putting it into practice: One-to-one volunteering and volunteering with a GP practice/care home

The training programme was delivered twice in Year 1: once in Sept/Oct 2013 and then again Jan/Feb 2014. Twenty-eight Future Matters volunteers completed the Level 1 training by February 2014 and twenty-two volunteers completed the Level 2 training by February 2014.

In order to assess the volunteers learning during the training programme, the volunteers were asked to complete a pre and post training knowledge and confidence questionnaire. The results of these questionnaires can be seen in Appendix 1.

As part of the training programme, the Future Matters volunteers were encouraged to complete their own end of life care plans. This was so they gained an understanding of the planning process for themselves before they began to support others to complete their plans. It also enabled them to become role models to others. Table 4 outlines the plans that the volunteers had in place at the start of the training and those they had put in place by the end. Encouragingly by the end of the training 16 of the volunteers had written their own advance care plan, 14 had recorded their funeral wishes and 22 had discussed their wishes with someone important to them.

Table 4: Volunteers Own Planning for the Last Years of Life, Pre and Post training programme

| I have..... | Pre-training | Post-training | Change |
|--|--------------|---------------|--------|
| 1. Discussed my own wishes with those who are important to me (partner, family friends) | 14 | 22 | +8 |
| 2. Discussed my own wishes with those who are responsible for my medical care (GP, consultant) | 1 | 2 | +1 |
| 3. Written down my own wishes e.g. Advance Care Plan or Preferred Priorities for Care | 2 | 16 | +14 |
| 4. Written a will | 15 | 15 | 0 |
| 5. Arranged Powers of attorney | 5 | 6 | +1 |
| 6. Recorded funeral wishes | 3 | 14 | +11 |

The training programme was evaluated by the volunteers and they highly rated the course: 100% of all participants indicated that they “would recommend the training to others”. See Appendix 2 for full details of the evaluation.

4. Community awareness raising events

Community awareness raising activities were delivered by Future Matter volunteers once they had completed their training. These activities were presentations to large audiences, workshops to medium or small groups and information stalls. The volunteers were trained to use a variety of interactive activities and tools to support the delivery of their events including short films, presentations, poems, quizzes, games and leaflets. At the end of the activity, the participants were given the opportunity to request an appointment with a Future Matters volunteer who could help them develop their plans.

- 98 community organisations were contacted by Age UK Islington. They were provided with information about Future Matters and/or asked if they would like Future Matters to deliver an activity for their clients.
- 17 events were delivered by the Future Matters volunteers between October 2013 and March 2014. See Table 5 for a list of events that were delivered and the number of people that attended. The Table also indicates the number of people that requested to have a one-to-one appointment with a volunteer.
- In total 262 members of the public were reached by these events.

| | Event Name | Activity | Date | No. attended | Follow ups |
|----|---|-----------------|--------------|---------------------|-------------------|
| 1 | AUKI - Drovers | Stall | 11.10.13 | 12 | 2 |
| 2 | Circle Support - older peoples event | Stall | 07.11.13 | 16 | 5 |
| 3 | Islington Pensioners Forum | Talk | 21.11.13 | 26 | 1 |
| 4 | AUKI - Duke of Edinburgh GTG | Workshop | 25.11.13 | 8 | 0 |
| 5 | Carers Rights Day, Islington Carers Hub | Stall | 29.11.13 | 16 | 5 |
| 6 | Disabled Older Peoples day | Stall | 03.12.13 | 10 | 3 |
| 7 | Dementia Awareness Day | Stall | 17.01.14 | 35 | 0 |
| 8 | Stacey Street Relatives Meeting | Presentation | 22.01.14 | 7 | 0 |
| 9 | Highbury New Park Relatives Meeting | Presentation | 22.01.14 | 17 | 1 |
| 10 | Lennox House Relatives Meeting | Presentation | 13.02.14 | 15 | 1 |
| 11 | Claremont | Workshop | 25.02.14 | 9 | 0 |
| 12 | Planning End of Life Care Event | Workshop | 11.03.14 | 23 | 0 |
| 13 | Older Persons Reference Group | Presentation | 07.03.14 | 31 | 10 |
| 14 | Manor Gardens Heart and Stroke Group | Workshop | 21.03.14 | 16 | 3 |
| 15 | LGBT event | Stall | 18.02.14 | 4 | 0 |
| 16 | Get Healthy Event, N19 | Stall | 18.02.14 | 6 | 0 |
| 17 | Mind Yourself event | Presentation | 25.03.14 | 9 | 3 |
| | | | Total | 262 | 41 |

Two case studies have been provided to give a flavour of the community workshops, the participants and how the sessions were delivered.

**Case Study 1 – Older Persons Reference Group (OPRG), Islington Town Hall , 21st Nov 13
Written by Nigel Taylor, Future Matters Volunteer**

Islington OPRG is funded by Islington Council and hosted by Age UK Islington. It was launched in September 2011 as a means of enabling older people to comment on issues that affect them so that Islington Council can improve its services for older people. At their regular group meetings there are normally a couple of presentations and Future Matters were asked to attend to present a session on planning for the last years of life.

At this meeting the group was made up of a good cross section of 30 older people. We introduced ourselves and explained what Future Matters covers and the background to the project. We showed two short films to break up the presentation. There was an excellent Q&A session covering such topics as body donation and where to keep documentation.

Following this, we chatted to members of the group informally and followed up by taking names of people who were interested in discussing Future Matters on a one to one basis. This group made up the bulk of people seen on a one to one basis early in 2014.

**Case Study 2 – The Claremont Project, 24-27 White Lion Street N1 9PD, 25th Feb 14
Written by Sarah Faulkner, Future Matters Volunteer**

An event was held at the Claremont Project on 25th February 2014. This project serves 700 active members between the ages of 55 and 100, providing educational, creative and leisure activities, with the aim of bringing people together to end isolation and promote well-being. One of the event participants described the Claremont Project as “quite psychologically minded”.

The event was attended by 9 people, aged between late 50’s and 83 years; all but one was female. One was of mixed parentage, the remainder being white.

The activities we used during the event were the Euphemisms game (thinking of all the words and phrases people use instead of saying “death” or “dying”), the Future Matters Quiz and the Conversation Card game which helps participants think about what might be important to them towards the end of their life. Discussion about the answers to the quiz enabled a broad based introduction to the subject of Advance Care Planning.

The participants engaged actively, were keen to receive information, to ask questions and discuss the issues covered. They raised additional issues which were of significance to them such as key-holding, referral to social services, and disposal of personal effects after death.

The time set aside for this event was used fully by the participants. It seems likely that the nature of the project in which the event was held, increased its chances of success.

As a result of this event, a tailored workshop was developed with the Claremont Project to be delivered during Dying Matters week on the subject of Wills & Power of Attorneys.

5. Attaching volunteers to 10 GP practices or Care Homes

Outcome 4:

Planned Outcome - 10 GP practices/care homes to have a Future Matters volunteers attached to their service by March 2014 so they can raise awareness with patients and care home residents and support, where appropriate, the completion of advance care plans;

Achieved Outcome - 10 services had a Future Matters volunteers attached to their service by March 2014

- Future Matters volunteers were attached to 3 GP practices, 4 Care Homes and an Extra Care Scheme.
- In addition, Age UK Islington has set up an internal referral system and one-to-one fortnightly appointment sessions as part of their Information and Advice Service.

Assessing volunteer's ability to carry out one-to-one sessions

At the end of the Level 2 training (Module 8), the Future Matters volunteers were assessed by the trainers to ascertain whether they had the appropriate skills and qualities, and were able to make the necessary commitment, to be attached to a GP practice or Care Home. The criteria they were assessed against are outlined in the box below:

Criteria that the volunteer were assessed against to be able to offer One-to-one appointments

Skills and qualities

- Has good communication skills (including verbal and active listening skills) demonstrated throughout the training programme
- Has demonstrated a non-judgemental attitude
- Has a good understanding of planning for the last years of life and advance care planning demonstrated by the end of the training programme

Commitment

- Able to volunteer at least 2 hours per week with a GP practice/care home

Table 6 outlines services where Future Matters volunteers were attached. Below the table is an explanation of how these services were selected or identified.

| | Organisation | Address | Notes |
|----|--|---|--|
| 1. | Age UK Islington | 6-9 Manor Gardens, N7 6LA | Thursdays twice a month |
| 2. | Partnership Primary Care Centre | 331 Camden Road, N7 0SL | Started Jan 2014 |
| 3. | Mitchison Road Surgery | 2 Mitchison Road, London, N1 3NG | Started Nov 2013 |
| 4. | Dartmouth Park Practice | 18 Dartmouth Park Hill, London, NW5 1HL | Member of Admin staff trained |
| 5. | Bridgeside Lodge Care Centre | 61 Wharf Road, Islington N1 7RY | Started Nov 2013 and finished mid April 14 |
| 6. | Lennox House Care Home | 75 Durham Road, N7 7DS | Started Nov 2013 and finished end March 14 |

| | | | |
|-----|---|--------------------------------|--|
| 7. | Stacey Street Nursing Home | 1 Stacey Street, N7 7JQ | Started Nov 2013 and finished end Jan 14 |
| 8. | Highbury New Park Care Home | 127 Highbury New Park, N5 2DS | Started Dec 2013 |
| 9. | Mildmay Extra Care Support Schemes | 20-26 Mildmay Park, N1 4PH | To start April 2014 |
| 10. | Mildmay Extra Care Support Schemes | 73 Mildmay Park, N1 4AQ | To start April 2014 |
| 11. | Hanley Primary Care Centre | 51 Hanley Road, London, N4 3DU | To start May 2014 |

Appointments at Age UK Islington

Very early on in the project it became apparent that the community awareness raising activities were generating a great deal of interest from members of the public, and attendees were requesting an appointment with a volunteer to help them develop their plans. Age UK Islington therefore decided to offer twice monthly appointments from their Manor Garden offices.

This service is now being managed as part of the Age UK Islington Information and Advice Service and is the projects' main source of referrals (see 'Numbers of Planning for last years of life conversations' section below).

Attaching volunteers to GP Practices

Through previous work in Islington, Gentle Dusk had identified that Mitchison Road Surgery and Dartmouth Park Practice were interested in the project and having a volunteer attached to their practice. Dartmouth Park was specifically interested in having a member of their administration team trained so they could offer support "in-house" instead of having a volunteer attached to their practice. The member of staff was trained in Sept 2013.

Information about the Future Matters project was also given out by Dr Patrick McDaid at a GP training event in October 2013. Two GP practices expressed an interest: the Mildmay Practice and Partnership Primary Care Centre. Meetings were held with these interested practices to outline the project and the commitment required. Following this meeting Mildmay Practice decided to withdraw due to lack of time to invest sufficiently in the project.

However, at the Mildmay practice meeting contact was made with a member of staff from the Mildmay Extra Care Support Scheme (Notting Hill Housing) who manage 3 schemes in Islington. Following meetings with the management team it was agreed that Future Matters would deliver two workshops for their customers and attach volunteers to their schemes to offer support to customers to develop their Advance Care Plans.

Attaching volunteers to Care Homes

The Islington Last Years of Life Steering Group suggested it would be helpful to attach volunteers to some of the care Homes to support residents, and the homes themselves, with Advance Care Planning. This process was supported by Tina Jegede (Lead Nurse for Quality & Assurance – Care Homes) who identified homes and arranged for Future Matters to meet with the care home staff. A number of meetings were held with the care homes to outline the project, the commitment required and to discuss and agree the practicalities of delivering the service within the homes. Future Matters volunteers were attached to 4 care homes (see Table 6 above).

Clients are seen by a Future Matters Volunteer over 1 to 3 sessions depending on the clients' needs. Most sessions last between 1hr and 1½hr. All planning for the last years of life issues are covered (i.e. advance care planning, Wills, Powers of Attorney and recording funeral wishes) and the clients are free to opt in or out of any support in taking the plans forward. Once a client has completed their Advance Care Plan it is handed over to the GP or care home by the patient for a discussion and for recording in the clients notes. Clients are also encouraged to discuss and share this with those important to them and anyone else involved in their health or social care.

Below is a case study of how one of our Future Matters volunteers based at Age UK Islington's Information and Advice Service has supported a client to develop her end of life care plans.

Case Study – Mary (Aged 93 years)
Written by Rick Taylor, Future Matters Volunteer

Mary was referred to Future Matters at Age UK Islington Information and Advice Service as she wanted to put some plans in place. The client was very interested in discussing her end of life care and was particularly annoyed that she had been resuscitated after a heart attack 2 years ago.

My first task was to determine if she had full mental capacity. She did not appear to be particularly depressed and stated that she was tired and exhausted of life and that she had been lucky enough to have a long and good life, but now felt that it was time to put her affairs in order and record her wishes for a natural death.

After the first session, I contacted the client's social worker in order to clarify her mental state and was told that she was deemed to have full mental capacity but was becoming increasingly frail.

During the course of our three sessions the client was keen to complete all areas of the Future Matters programme (advance care planning, writing a Will, recording funeral wishes, and registering as an organ donor). She wanted some time to talk about her life and current situation, and most of the first session was taken up with this.

During the second meeting, we made good headway with completing her advance care plan where she was able to make important decisions about her end of life care as well as funeral planning, Power of Attorney and also some of the more personal aspects of the last days.

The final session was mainly taken up with her request to become an organ donor. On taking advice on this I was able to inform her that due to her age, only certain body parts would be used so I provided information on an alternative of full body donation to aid medical education. She was very keen on this expressing a desire to be useful after her death.

On advice from my line manager I was able to tell her that I could obtain the relevant forms and then talk her through the process. However, I was not allowed to fill the forms in on her behalf, and told her that she would need to do this herself in conjunction with a close relative. She seemed happy to do this and took the forms away along with three copies of her completed Advance Care Plan. I explained to her that she should keep one of these herself, give one to her GP and one to a close relative.

She seemed very happy, if not a little sad to have completed our sessions. However, she seemed happier in herself and told me that she thought she had taken back some control over her last years. I considered this to be a very successful outcome for the client and for Future Matters.

6. Numbers of Planning for last years of life conversations

Outcome 5:

Planned Outcomes

- 150 Last Years of Life Planning conversations held by the Future Matters volunteers by end of December 2013
- 400 Last Years of Life Planning conversations by the end of March 2014;
- To count the number of advance care plans, Wills and funeral plans developed.

Achieved Outcomes

- 169 Last Years of Life Planning Conversations were held by the volunteers by End Dec 2013
- 420 conversations were held by end of March 2014: 262 via community events and 158 on a one-to-one basis

As a result of one-to-one support with a volunteer:

- 12 people have completed an Advance Care Plan
- 11 people have written a Will
- 9 people have organised a Power of Attorney
- 10 people have recorded their funeral wishes
- 5 people have registered as an organ donor

NOTE: 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 are unable to capture this information.

It is also important to note that the individual appointments at the 10 settings only began in November 2013 so most of this activity has been achieved over a 5-month period.

The Future Matters project has been using Survey Monkey to monitor the number of conversations and one-to-one appointments that the volunteers have had with members of the public. Volunteers are expected to complete a brief Survey Monkey form after every “conversation” they have had with a client. The definition of a “conversation” is outlined in box below.

The definition of a Last Years of Life Planning Conversation

“An interaction with another person about planning for the last years of life. The interaction could be on an individual basis or in a group setting. The interaction will last for at least 5 minutes and the person must be offered (when appropriate) the opportunity to meet with a Future Matters Volunteer on another occasion to help them develop their plans. If a volunteer meets with a person on more than one occasion each meeting would be a “conversation. Written information will be given as part of a conversation where appropriate”.

This section of the report provides a summary of the clients reached through one to one conversations and through the individual appointments that the volunteers had with clients at the 10 settings outlined in the previous session. This section also outlines the outcomes of these interactions i.e. the plans that clients have put in place as a result of the volunteer support.

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

- 158 people were reached via one-to-one conversations held by the volunteers.
- 63% of those reached were female and 37% were male. One third (33%) of those seen were aged 51-65 year olds, 24% were 66-75 years and 22% were Over 75. See Table 7.

| | Response Percent | Response Count |
|--------------------------|-------------------------|-----------------------|
| 18-35 | 4.5% | 7 |
| 36-50 | 16.8% | 26 |
| 51-65 | 32.9% | 51 |
| 66-75 | 23.9% | 37 |
| Over 75 | 21.9% | 34 |
| answered question | | 155 |
| skipped question | | 3 |

- Just under two-thirds of the clients reached via one-to-one conversations were White British (60%), followed by Black British Caribbean (10.5%) and White Irish (9%). See Table 8.

| | Response Percent | Response Count |
|---------------------------------|-------------------------|-----------------------|
| Asian/Asian British - Indian | 2.0% | 3 |
| Asian/Asian British - Other | 0.7% | 1 |
| Black/Black British - African | 2.0% | 3 |
| Black/Black British - Caribbean | 10.5% | 16 |
| Black/Black British - Other | 2.0% | 3 |
| Chinese | 0.7% | 1 |
| Mixed - White & Black African | 0.7% | 1 |
| Mixed - White & Black Caribbean | 0.7% | 1 |
| Mixed - Other | 2.0% | 3 |
| White - British | 59.9% | 91 |
| White - Irish | 9.2% | 14 |
| White - Other | 7.9% | 12 |
| Other | 2.6% | 4 |
| If Other (please specify) | | 11 |
| answered question | | 152 |
| skipped question | | 6 |

Referral routes

- Table 9 shows that the majority of the clients reached via the one-to-one conversations were by self-referral (65.8%). This means that these clients were either approached directly by the volunteers or they approached the volunteer for a conversation. These conversations began from September 2013 when the volunteers started their training.
- 13% of the clients were seen by volunteers from Age UK Islington Advice and Information Service. These conversations took place between October 2013 and end March 2014.
- 11% of the clients reached were care home residents. These conversations took place between November 2013 and end March 2014.

- There were a small number of referrals from the 2 GP practices where the volunteers were attached. These conversations took place between October 2013 and end March 2014.

| | Response Percent | Response Count |
|---|-------------------------|-----------------------|
| Self-referral | 65.8% | 104 |
| Age UK Islington (Information & Advice) | 12.7% | 29 |
| Bridgeside Lodge Nursing Home | 1.9% | 3 |
| Highbury New Park Nursing Home | 0.6% | 1 |
| Lennox House Nursing Home | 8.2% | 13 |
| Stacey Street Nursing Home | 0.0% | 0 |
| Mitchison Road GP Practice | 1.3% | 2 |
| Partnership Primary Care GP Practice | 0.0% | 0 |
| If Other (please specify) | | 39 |
| answered question | | 158 |

Topics discussed during the one-to-one conversations

- The topics that can form part of a 'planning for the last years of life conversation' are listed in Table 10. The topics that were most discussed during the one-to-one conversations were advance care planning (67%), funeral planning (64%) and writing a Will (61%).

| | Response Percent | Response Count |
|---|-------------------------|-----------------------|
| Advance Care Planning | 67.1% | 106 |
| Discussing ACP or their wishes with family/friends | 57.0% | 90 |
| Discussing ACP or their wishes with their GP/health professionals | 32.3% | 51 |
| Wills | 60.8% | 96 |
| Powers of Attorney | 48.7% | 77 |
| Funeral Planning | 63.9% | 101 |
| Organ Donation | 26.6% | 42 |
| Other | 7.0% | 11 |
| If Other (please specify) | | 16 |
| answered question | | 158 |



Plans completed by the clients as a result of volunteer support

- Table 11 provides a summary of the plans that were completed by clients as a result of support from a volunteer. It is important to note that 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. We have been unable to capture these numbers.
- It is also important to note that the individual appointments at the 10 settings only began in November 2013 so most of these plans have been put in place over a 5-month time period.

| Table 11: Plans completed by the clients as a result of volunteer support | | |
|--|-------------------------|-----------------------|
| | Response Percent | Response Count |
| Completed an Advance Care Plan (ACP) | 7.6% | 12 |
| Discussed their ACP or their wishes with family/friends | 14.6% | 23 |
| Discuss their ACP or wishes with their GP | 3.2% | 5 |
| Written a Will | 7.0% | 11 |
| Organised a Power of Attorney | 5.7% | 9 |
| Written a Funeral Plan | 6.3% | 10 |
| Registered as an Organ Donor | 3.2% | 5 |
| None of the above | 44.9% | 71 |
| Don't know | 15.2% | 24 |
| Other | 12.0% | 19 |
| If Other (please specify) | | 58 |
| <i>answered question</i> | | 158 |

Section Five: Additional Project Outcomes

Alongside our planned project outcomes, we had two very successful additional outcomes. These are mentioned here as they have been instrumental in the success of the project but took up a significant amount of time from the Age UK Islington and Gentle Dusk project teams.

Talks/presentation to professionals about planning for last years of life

As organisations within Islington began to hear about the Future Matters project, staff from Age UK Islington and Gentle Dusk were requested to speak to staff groups about the project and what it offers. Many of the presentations also included an element of staff training about planning for the last years of life. For example the talk to the Social Work team included a screening of a Dying Matters video and facilitating a discussion about how they could begin conversations about death and dying with their clients.

Table 12 provides a summary of the presentations that the Future Matters staff team made during Year 1.

Table 12: Presentations made to organisations/services by Future Matters staff team

| | Date | Organisation |
|---|---------------------------|--|
| 1 | 26 th Nov 13 | Islington Elipse Palliative Care Team |
| 2 | 26 th Nov 13 | Age UK Islington Enablement Service (including Locality Navigators) |
| 3 | Dec 13 | Age UK Islington Information & Advice Service |
| 4 | 23 rd Jan 14 | Islington Last Years of Life Steering Group |
| 5 | 12 th Feb 14 | Residential and Nursing Review Social Work Team and the North On-going Support and Review Social Work team |
| 6 | 14 th March 14 | Whittington Hospital Care of the Older Persons Team |
| 7 | 24 th March 14 | Whittington Hospital Respiratory Team |

Development of a Future Matters advance care planning form

At the start of the project the Preferred Priorities for Care advance care planning document was used as the project's main template for completing an advance care plan as this had been developed by the National End of Life Care programme (no longer in existence). However, very early on it became apparent that both the Future Matters volunteers and the public found this document difficult to complete due its lack of structure and direction.

It was also challenging for the project as many organisations/services have their own advance care planning document and there is no one form that is used consistently by everyone in the borough. The Future Matters project therefore decided to develop their own advance care planning tool that would bring together all elements of planning for the last years of life into one document. It would also provide enough information within the document that someone could complete the form by themselves without the support of a professional or volunteer. It was hoped that this would increase the number of advance care plans completed.

The Future Matters advance care plan was completed, with volunteer input, in April 2014 and is available upon request.

Appendix 1: Pre/Post training knowledge and confidence questionnaires

Training in Sept/Oct 2013

| Knowledge and Confidence | Pre-training confidence/knowledge | Post-training confidence/knowledge | Change in knowledge/confidence |
|--|-----------------------------------|------------------------------------|--------------------------------|
| How knowledgeable are you about: | | | |
| 1. Planning for the last years of life and what it involves | 54 | 101.5 | +51.5 |
| How confident do you feel about: | | | |
| 2. Starting a conversation about your own wishes | 76 | 105 | +38 |
| 3. Starting a conversation with close family about their wishes | 75 | 98 | +30 |
| 4. Starting a conversation with someone you don't know about planning for the last years of life | 74 | 97.5 | +34.5 |
| 5. Supporting someone to start a conversation about death and dying with family and friends | 70 | 91.5 | +30.5 |
| 6. Running an awareness activity about planning for the last years of life? | 56 | 90 | +40 |

Training in Jan/Feb 2014

| Knowledge and Confidence | Pre-training confidence/knowledge | Post-training confidence/knowledge | Change in knowledge/confidence |
|--|-----------------------------------|------------------------------------|--------------------------------|
| How knowledgeable are you about: | | | |
| 1. Planning for the last years of life and what it involves | 72 | 99 | +27 |
| How confident do you feel about: | | | |
| 2. Starting a conversation about your own wishes | 97 | 110 | +13 |
| 3. Starting a conversation with close family about their wishes | 90 | 103 | +13 |
| 4. Starting a conversation with someone you don't know about planning for the last years of life | 68 | 98 | +30 |
| 5. Supporting someone to start a conversation about death and dying with family and friends | 67 | 99 | +32 |
| 6. Running an awareness activity about planning for last years of life? | 51 | 85 | +34 |

Appendix 2: Summary of Final Training Evaluations

Training in Sept/Oct 2013

Number of completed evaluation forms = 12

| | Very good | Good | OK | Poor | Very poor |
|---|------------|------|-----------|------|-----------|
| The venue | 83% | 17% | 0% | 0% | 0% |
| The refreshments | 50% | 50% | 0% | 0% | 0% |
| The length of the training i.e. 3 ½ days | 42% | 33% | 25% | 0% | 0% |
| The length of each day i.e. 9.30am-4pm | 50% | 42% | 8% | 0% | 0% |
| The organisation of the training | 83% | 17% | 0% | 0% | 0% |
| The facilitation of the training | 92% | 8% | 0% | 0% | 0% |
| The handouts and supporting materials | 90% | 30% | 0% | 0% | 0% |
| Thinking about the training overall, how would you rate it? | 67% | 33% | 0% | 0% | 0% |
| | Yes | | No | | |
| Would you recommend the training to others? | 100% | | | | |
| Do you feel ready to be a Future Matters Volunteer? | 100% | | | | |
| If No, can you tell us what else you need? | | | | | |
| <ul style="list-style-type: none"> • Yes, but a bit wobbly about getting started and how to engage. Some lack of clarity about how AUKI will support us on on-going basis. | | | | | |

What was the best thing about the training?

- Sharing knowledge, ideas, experience. Facilitator's knowledge, ideas, experience. Group work – getting to know each other
- The steady progress of building up our knowledge for the role. The structure of the information was concise. Variety of activities helped to make me feel involved
- Accessibility, knowledge and enthusiasm of trainers. Demystifying whole area of end of life preparation. Getting me to write my own ACP/PPC and ADRT and getting me to book a Will writing session
- Concise and informative
- I was surprised about how in depth the training was and I mean that in the best way possible. The training was so well organised and followed a clear path and felt very digestible given the amount of information.
- Power of Attorney, solicitors etc and planning our own funeral
- Very organised and professional. Well-structured training with nice pacing and good mix of information and practical activities. Excellent handouts and support materials. Skilled trainers – good encouraging atmosphere, openness, respectful and acknowledging and experience and skills of the group
- Taking control of own care plan. Insight to effective will (and legal). Various funeral choices and support for the under privilege people

- Role play – if time could be made do more on other days
- The content was very relevant and presented very well using a great variety of platforms. Tough subject sensitively and thoroughly covered
- Getting your own plans in order and understanding how to help others

How could the training be improved?

If you have rated anything above 'Ok', 'Poor' or 'Very Poor', please tell us how we can make things better.

- I think making a specific time slot for personal stories that don't interfere with training time and get us off point. Perhaps our stories could be held off until certain time frames throughout the day.
- Printing material for field work
- If there is a gap in my confidence we did not spend enough time going through some of the options and pitfalls one might fall into writing an ACP. This is a specific role play we might have done with several of our volunteers
- Perhaps just a brief explanation of the context i.e. NHS priorities and funding reason (Islington Council and Age UK)

Please feel free to write down any other comments you have about the training.

- It was great and I feel very confident and capable because of this training. Well done!
- It is likely that this course will always feel rushed. For me, the email of the handout booklet to allow me to read through the day before really helped with my take up of information on the day
- Enjoyed the delivery of the teaching – interactive and informative

Training in Jan/Feb 2014

Number of completed evaluation forms = 14

| | Very good | Good | OK | Poor | Very poor |
|---|------------|------|----|-----------|-----------|
| The venue | 64% | 36% | 0% | 0% | 0% |
| The refreshments | 93% | 7% | 0% | 0% | 0% |
| The length of the training i.e. 3 ½ days | 64% | 29% | 7% | 0% | 0% |
| The length of each day i.e. 9.30am-4pm | 64% | 29% | % | 0% | 0% |
| The organisation of the training | 86% | 7% | 0% | 7% | 0% |
| The facilitation of the training | 86% | 14% | 0% | 0% | 0% |
| The handouts and supporting materials | 79% | 14% | 0% | 0% | 0% |
| Thinking about the training overall, how would you rate it? | 79% | 21% | 0% | 0% | 0% |
| | Yes | | | No | |
| Would you recommend the training to others? | 100% | | | | |
| Do you feel ready to be a Future Matters Volunteer? | 79% | | | 21% | |

If No, can you tell us what else you need?

- Probably just some practice!
- More time to familiarise myself with materials and digest it

What was the best thing about the training?

- Improving knowledge and confidence
- Developing a feel for issues for oneself
- Conversations with other trainees, the content was really comprehensive. It feels like an exciting project to get involved with
- Discussion and sharing ideas and information. Access to resources.
- Exchanging ideas. Materials used – variety was important. Solicitor and funeral directors attending sessions. Materials and knowledge I can use for my practice
- The diversity of all the subject matter
- I have enjoyed the training immensely. The discussions were enlightening and a great eye opener, in terms of putting ones house in order. One of the best things about the training is the group work. In addition the films, games and various speakers that inform us.
- Varied activities and pace. Supportive environment
- Structure and interaction
- Presentations by guest speakers – funeral director, solicitor etc. videos

How could the training be improved?

If you have rated anything above 'Ok', 'Poor' or 'Very Poor', please tell us how we can make things better.

- Maybe more role plays for one-to-ones
- I thought the first day for such an intense course should be less hours, which could be a half day
- I need more practice, perhaps role play

Please feel free to write down any other comments you have about the training.

- Thanks for a really enjoyable (!) course – I'm looking forward to putting it into practice!
- A lot of information to retain, some participants may have experience/training days at a fast pace. Could be increased by 1 day.
- It was much more fun than I expected.
- Thank you for a brilliant course, so professionally and competently delivered.