

IN PARTNERSHIP WITH





Islington Future Matters Annual Report

April 2022 - March 2023



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CASE STUDY



I have an elderly friend who is 89 years old. When her husband John, became ill, I asked her the question, "Have you any idea what John would want in the event that he could no longer communicate his wishes?" She replied that she didn't and we agreed that whilst he was currently "fine", it would be a good idea to get his wishes written down on paper.

As a trained, experienced Future Matters volunteer, I know that when it comes to protecting your future wishes for your health and care, if you have discussed and recorded your wishes or those of the people that are close to you, there is a far greater chance of these wishes being met. It also means that the members of the family that are left picking up the pieces after a death do not have to add to their grief and stress by arguing about or guessing what the person that they cared for might have wanted. It is there written down on paper to guide them. As a result, it can take away a lot of worry, angst and conflict. It can also make the grieving process a bit easier, because you feel that you have done what you can for the person you cared for.

Following the conversation with my friend, I sat down with her husband, John, and spent a couple of hours talking with him about what his wishes were. It sounds like this would have been a potentially difficult, dreary or depressing two hours, but it was none of these things. It might seem strange, but it is actually something which can be fun. The conversation is an exploration of what you're doing now, what you care about and what you'd like to happen, for example, in the event that you were critically ill.

Whilst we managed to record a number of John's wishes, we didn't quite complete it, as he died very suddenly. Then three months later, his oldest daughter's husband died. Two widows from two generations were left having to deal with similar situations. The difference being that my friend was able to refer to the Advance Care Plan that had gone a long way in recording her husband's wishes, whereas her daughter did not have the benefit of anything like this to guide her.

The reason why she did not have anything to guide her on her husband's wishes? As with so many people, this was simply that she and her family had not got round to talking about it.

EXECUTIVE SUMMARY

Future Matters (FM) is an advance care planning service and public health approach to end of life care planning. Future Matters helps lift the taboo, by facilitating open discussions about death, dying and bereavement in local communities. It raises awareness of end of life care planning and supports clients to complete their plans, including Advance Statements and Lasting Powers of Attorney (LPAs).

Future Matters Islington has been commissioned by Islington Clinical Commissioning Group (CCG)/Integrated Care Board (ICB) since 2013. In its 10th year, the service has grown, continues to exceed its targets and has doubled the number of plans being completed. In Year 10 (2022/2023):

- ✓ 366 members of the public were reached through awareness raising events. These included Death Café's, live and online presentations on LPAs, Advance/Universal Care Plans, community events and events for carers.
- ✓ 238 enquiries were received for the FM Advance Care Planning Service.
- ✓ **116 clients** had one-to -one appointments for Advance Care/End of Life Planning.
- ✓ 183 LPAs, 6 Wills, 2 Advance Decision to Refuse Treatment and 1 Gentle Dusk Advance Care Plan (ACP) were completed as a result.
- ✓ 50 clients requested information about Advance Care/End of Life Planning resources for their own completion.
- ✓ 195 Downloads of end of life care planning resources from <u>https://gentledusk.org.uk/resources/</u>

For further details and breakdown, refer to page 7: Islington Future Matters Service - Our Year in Numbers.

Summary of the Year

We continue to deliver a thriving community service, raising awareness and facilitating conversations within **varied settings and to a diverse audience**. From Dying Matters Week events in accessible local settings such as shopping centres and parks to workshops in community centres and regular Death Cafés, our events are very successful and the feedback is overwhelmingly positive (see feedback, page 8).

Our **communications strategy** and service publicity have also significantly contributed to raising awareness of end of life care planning through the use of local press (see Islington Tribune article, page 17), newsletters, mailouts as well a significant amount of activity on social media, all reaching thousands of local residents.

Referrals to our service originate mainly from self-referrals but also from our community and online events, word of mouth, and close links with Age UK Islington teams. We also get referrals via social care and health professionals.

We are especially proud that demographic data from our service demonstrates that the ethnicity and age range, deprivation and health conditions of our service users continues to be diverse. Future Matters reaches out, engages and supports deprived communities. 80% of our clients come from medium to high deprivation circumstances; 27.5% of our clients are from Asian, Black and Mixed Ethnicity making Future Matters a real solution to end of life care planning for all. See Table 2: Future Matters clients Demographics compared to Islington Population and Adult Social Care Clients, page 12. Our success is thanks to a dedicated team made up of experienced professionals and volunteers living in Islington as well as a strong partnership between Gentle Dusk and Age UK Islington.

WHAT IS FUTURE MATTERS?

Future Matters is a community-based solution for strengthening advance care planning in the UK. Gentle Dusk works in partnership with local organisations to set up Future Matters Services, reaching people where they are, with the information and support they need to plan their futures.

Our Future Matters training course equips volunteers with knowledge, skills and tools to deliver both community events and one-to-one support for residents planning their emergency and advance care wishes, financial and legal affairs. Every Future Matters service is tailored to the local community. As well as advice and planning, Future Matters delivers a range of accessible events that inform and empower people to voice their choices.

First commissioned by NHS London in 2010, the FM programme has benefitted from continued monitoring, development, and improvement. Since 2013, for Islington we have partnered with Age UK Islington (AUKI) offering this unique service to Islington residents and/or people with a GP in Islington. Operating from the AUKI offices with a dedicated team of fully trained Future Matters volunteers. All our core staff and volunteers live in Islington.

How Future Matters helps local residents

In a 2021 Marie Curie survey of public attitudes to death and dying, only 14% of respondents said they had talked about death and dying and their end of life wishes; 51% felt that as a society we do not talk enough about death and dying; Only 14% had written down wishes for the care that they wanted (although 90% of people consider it important); and 78% of people were unaware of the term 'advance care plan'.

Future Matters adopts a public health approach to encouraging more open conversations about death and dying, informs residents about end of life care planning and supports local residents to complete their end of life care plans.

Public awareness

By delivering accessible presentations, workshops and events in the local community and online, Future Matters increases public awareness of end of life care planning. By delivering and facilitating regular Death Café's, Future Matters supports discussions to lift the taboo and enables more open conversations as well as better knowledge of end of life planning. By delivering engaging communication campaigns, Future Matters helps raise the profile of these sensitive conversations.

End of life care planning

Future Matters provides accessible one-to-one appointments to help local residents:

- Understand and set up LPAs.
- Make an ACP to record their health and treatment wishes.
- Share their wishes with those who are important to them.

Further information regarding the Islington Future Matters Service is available on Gentle Dusk and AUKI websites: <u>https://gentledusk.org.uk/future-matters/</u> https://www.ageuk.org.uk/islington/our-services/future-matters-service/

FUTURE MATTERS SERVICE - What the Professionals say...

"Future Matters is a one stop shop for important planning for last years and end of life, whenever that might be."

Dr Patrick McDaid GP Principal - Mildmay Medical Practice





"Thinking about the future is important for us all to do. Though it might seem frightening, ignoring it only makes it harder when the time comes. We owe it to ourselves and our friends and families to share our wishes."

Dr Libby Sallow Palliative Care Consultant, Working in the Community

"Future Matters is an important service that helps some of our residents make plans for the end of life and better prepare for their own passing or that of their loved ones."

> Dr Patrick Schrijnen End of life Care Commissioner for North and Central London





"Future Matters provides creative ways to engage with the often taboo topic of death and dying and death cafes in particular can bring about surprising connection to self and others too."

Dr Beth Griggs GP Clerkenwell Medical Practice

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ISLINGTON FUTURE MATTERS SERVICE - OUR YEAR IN NUMBERS

Our Key Performance Indicators

Our targets for the year were to have achieved:

- **150** Public Awareness Engagements. These included Death Cafés and community events (online and/or face-to-face).
- **120** Formal End of life Care Plans: Lasting Powers of Attorney (LPA) or Urgent Care Plans (UCP).

The Scope of the Future Matters Service

- A more empowered community.
- More open end of life discussions.
- More ACPs, advance statements, LPAs and other plans in place.
- More people cared for and dying in their preferred place.
- Less unwanted futile treatments and less unnecessary hospital admissions.
- Reduced barriers to end of life conversations with health professionals.

Our Outcomes and Impact

The Future Matters team reached out to 366 people made up of the Public and Healthcare Professionals.

Breakdown attendees:

- 182 Future Matters Events
- **184 Outreach Community Events** Presentations were made to local community groups and Healthcare Professionals. Attendees included **126** carers.

183 Formal End of life Care Plans were completed:

- 93 Lasting Powers of Attorney: Financial & Property
- **90** Lasting Powers of Attorney: Health & Welfare

Other Plans:

- 6 Wills
- 2 Advance Decision to Refuse Treatment
- 1 Gentle Dusk Advance Care Plan (ACP)

It should be noted that the number of ACPs were significantly lower compared to our usual service outcomes in previous years. This was in part a commissioning requirement to focus on LPA's as well as the impact of My Co-ordinate my Care (patient portal for ACPs) being transferred to the Universal Care Plans from 1 April 2022, which to date does not have a patient portal for initiating/editing by patients.

- **238** Enquiries were received for the FM Service in the year.
- **230** Total clients.
- **50** Requested information about Advance Care/End of Life Planning resources for their own information and completion.
- **116** Requested client appointments. Total being **159** FM appointments (some clients requiring 2nd/3rd appointments).
- **64** Cases are in progress.

ISLINGTON FUTURE MATTERS SERVICE - OUR YEAR IN NUMBERS (continued)

Since the relaunch of the Gentle Dusk website earlier in the year <u>https://gentledusk.org.uk/resources/</u> there have been **195** of downloads (the majority of which were downloaded following our public or health professionals' presentations/event):

- **115** ACPs
- 40 LPAs Key Information
- 25 Funeral Planners
- 15 Will Planners

FUTURE MATTERS - PUBLIC AWARENESS EVENTS

A total of 22 awareness raising events were delivered to 366 members of the Public and Healthcare professionals. These activities included talks and presentations (live and online), information stalls at a variety of events, workshops and Death Cafés (see Table 1: Awareness raising events delivered by Future Matters - April 2022 to March 2023, page 9).

Death Cafés

In our Death Cafés, local residents and health professionals welcome the opportunity to have a safe and supportive space to talk about death, dying, bereavement and end of life care planning. It is a place where they can open up and be honest about death from whatever perspective they wish.

What participants say...

- I found the Death Café excellent.
- A privilege to have a rare chance to talk about death with skilled facilitators. This is such an important part of all our lives but not discussed often and remains taboo. Particularly relevant to us in general practice who meet many people approaching end of life.
- Thank you to the facilitators for providing an open space for us to reflect on our experiences both professionally and personally.
- Honest, rewarding and heartwarming.
- The facilitators were excellent!
- More Death Cafés please.



As part of these community awareness raising activities, we inform people about Advance Care Planning as well as the Future Matters Service and provide them with an information flyer to take away. If they are interested in an appointment to see a Future Matters volunteer for a one-to-one appointment for further individualised information and/or to put some plans in place, their contact details are taken by the volunteer and they are then contacted by Age UK Islington and given an appointment at a time and a place that suit their needs.

Table 1. Awareness raising events delivered by Future Matters - April 2022 to March 2023

DATE	NAME OF EVENT / LOCATION	ТҮРЕ	Number Attendees
1. Tuesday 3 May	Future Matters Service – Islington Green	Information Stall	20
2. Wednesday 18 May	Future Matters Service – St Luke's Community	Live Presentation	51
3. Wednesday 8 June	Future Matters Service – ICH Carers Week Angel Central & Whittington	Information Stall	20
4. Thursday 9 June	Lasting Powers of Attorney and Death Café (for GPs	Workshop	55
5. Thursday 16 June	Lasting Powers of Attorney/Wills	Online Presentation	12
6. Thursday 30 June	Advance Care Planning (My Co-ordinate my Care)	Online Presentation	8
7. Saturday 16 July	Saturday 16 July Future Matters Service – Soul in the City Event		5
8. Saturday 27 August	Future Matters Service – Hugh Cubitt Centre, N1 9QZ		15
9. Saturday 3 September	Future Matters Service – The Walter Sickert Centre N1 2FB	Information Stall	10
10. Tuesday 20 September	Lasting Powers of Attorney/Wills	Online Presentation	17
11. Thursday 23 September	Death Café at Almeida Theatre Café	Live Event	10
12. Tuesday 4 October	Death Café at Clerkenwell Medical Centre	Live Event	7
13. Tuesday 22 November	Lasting Powers of Attorney/Wills	Online Presentation	21
14. Thursday 24 November	L4. Thursday 24 November Future Matters Service – Carers Rights Day (Public)		6
15. Thursday 24 November	Thursday 24 November Future Matters Service – GP Forum		40
16. Friday 25 November	Friday 25 November Death Café at Almeida Theatre Café		14
17. Mon 9 / Mon 31 January	Future Matters Service – Public (via telephone)	Helpline	14
18. Thursday 7 February	Lasting Powers of Attorney/Wills	Online	6
19. Wednesday 15 February	Future Matters Service – Amwell Medical Centre GPs/Team	Meeting	15
20. Friday 24 February	Death Café at Almeida Theatre Café	Live Event	12
21. Wednesday 22 March	ay 22 March Future Matters Service – VCS Marketplace Islington Town Hall		N/A
22. Saturday 25 March	Future Matters Service – Brickworks Community Centre	Live Presentation	8

FUTURE MATTERS: ADVANCE CARE PLANNING SERVICE

Appointments with a trained FM volunteer are available for those residents who wish to actively plan and record their wishes for their end of life. This could include completing an ACP/Advance statement; making a LPA, or information about Wills, funeral wishes/plans, organ/tissue/body donation.

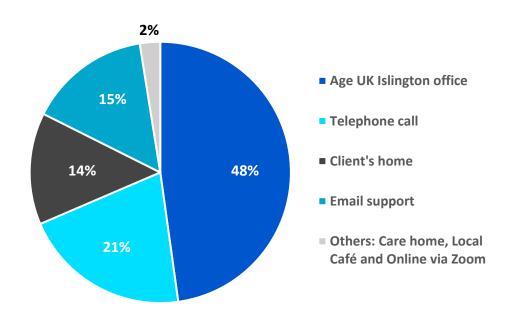
Our Advance Care Planning Service received **238 enquiries** this year from a total of 230 clients. **50 requested information** about advance care/end of life care planning resources with no further support. **116 clients** requested appointments, some clients requiring 2nd or 3rd appointments.

A total of **159 Future Matters appointments** were delivered. At the end of the year, 64 cases were still in progress.

A total of **183 advance care plans** were put in place as a result of the Future Matters appointments.

- 93 of these plans were LPAs Financial and Property
- 90 were LPAs Health and Welfare
- A further 9 plans were completed: 6 Wills, 2 Advance Decision to Refuse Treatment and 1 Gentle Dusk ACP

We offer our advance care planning support via email, telephone support, at Age UK offices or client's own home (including care home), whatever is most suitable to the client.



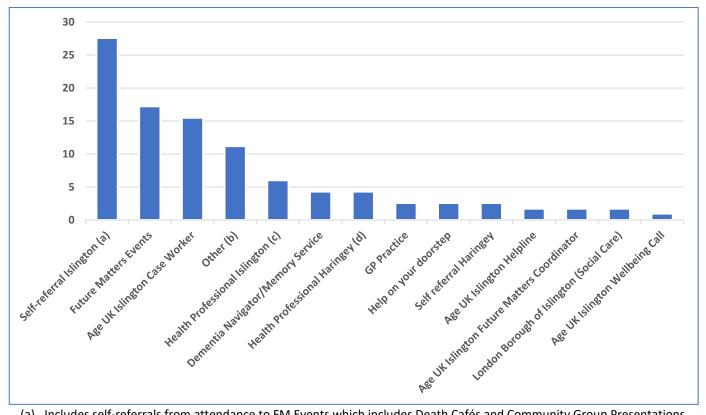
Graph 1. FM Support/Locations for Clients:

Referrals to Future Matters Service

The Future Matters Service is promoted to both public and professionals in Islington (see Communication Strategy, page 15). The team visit GP practice meetings, GP forums, Community Groups such as local social groups and Dementia Hubs. The service is well established now and the majority of local residents self-refer to the service or sign up for a one-to-one appointment after having attended one of the community events or presentations.

The online or in-person presentations include information regarding the Future Matters Service and also a number of subjects including Advance Care Planning, LPAs, Funeral Planning and Wills.

Future Matters volunteers also become champions and refer friends, family, people from their communities. See the graph below for breakdown of referral routes to our advance care planning service this year.



Graph 2. Breakdown of Referrals

(a) Includes self-referrals from attendance to FM Events which includes Death Cafés and Community Group Presentations (onsite and online).

- (b) Personal referrals from FM volunteers.
- (c) For example, hospital doctor, nurse or district nurse.
- (d) For example, hospital doctor, nurse or district nurse and includes Dementia Hubs.

DEMOGRAPHICS

The majority (68%) of our clients are 65 years of age and above. 9% of our clients are Asian, 16% Black, 2.5% Mixed Ethnicity and 52.2% White. 80% of our clients were from medium to high deprivation with 38% from high to very high deprivation.

Table 2. FM clients' D	Demographics compared t	o Islington Adult Social C	Care and Islington Population
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	Islington Adult Social Care	Islington Population	Future Matters
	Demographics 2021-22	ONS Census 2021	Demographics 2022-23
Age	46.5% 18-64	73.3% 18-64	32% 18-64
	53.5% 65+	9.4% 65+	68% 65+
Gender	58.1% Female	52.3% Female	67% Female
	41.9% Male	47.7% Male	33% Male
Ethnicity	 6.25% Asian 21.0% Black 3.35% Mixed Ethnicity 59.7% White 9.7% Other 	 9.9% Asian 13.3% Black 7.5% Mixed Ethnicity 62.2% White 7.1% Other 	 9% Asian 16% Black 2.5% Mixed Ethnicity 52.5% White 20% Not specified
Housing	No data available	40.2% Social rented	 37% Living with others in rented social housing 37% Living alone in rented social housing 26% Other
Long Term		 77.7% No long term physical or	100% have one or more Long
Conditions		mental health condition 84.1% Good to Very good health 10.4% Fair Health	Term Condition
Deprivation	25% Very High 23.7% High 19% Medium 18.7% Low 13.8% Very Low	No data available	9% Very High 29% High 42% Medium 11% Low 1% Very Low 8% Not known

All our clients have a variety of health conditions such as arthritis, diabetes, heart disease, dementia, depression, stroke, Chronic Obstructive Pulmonary Disease (COPD) and Alzheimer's. See Table 3 for the full breakdown, page 13. It should be noted that in some instances the clients have more than one health condition.

Table 3. FM Clients' Health Conditions/Disabilities

Disabilities	Clients	Disabilities	Clients
Arthritis	37	Kidney Disease	2
Other (a)	41	Renal Failure	2
Diabetes	33	Thyroid Condition	2
Heart Disease	19	Dyslexia	2
Dementia	17	Learning Disabled - Other	2
Health Condition - Other	16	Bipolar Disorder	2
Depression	14	Hoarding	2
Stroke	13	Personality Disorder	2
Chronic Obstructive Pulmonary Disease	12	Post traumatic stress disorder	2
Alzheimer's	12	Blind	2
Cancer	12	Sensory - Other	2
Hearing Loss	10	Speech Impairment	2
Anxiety	7	Deafness	1
Limited Mobility	7	Declined	1
Frailty	7	End Of Life	1
Osteoporosis	5	Bells Palsy	1
Physically Disabled	5	Chronic Pain	1
Asthma	4	Motor Neurone Disease	1
Mental Health - Other	4	Neurological Condition	1
Back Pain	4	Obesity	1
Falls Risk	4	Psoriasis	1
Deaf	4	Autism	1
Partially sighted	4	Downs Syndrome	1
Epilepsy	3	Dual Diagnosis	1
Fibromyalgia	3	Eating Disorder	1
Multiple Sclerosis	3	Memory Loss	1
Parkinson's Disease	3	Unable to Walk	1
Learning Difficulty	3	Unable to Walk unaided	1
Schizophrenia	3	Wheelchair Mobile	1
Learning Difficulty	3	Deaf and Blind	1
Schizophrenia	3	Alcohol Misuse	1
Physical Impairment - Other	3	Drug and Alcohol Misuse	1
Amputee	2	Drugs Misuse	1
Emphysema	2	Substance Misuse - Other	`1

(a) Specific conditions outside of the classifications listed.

FUTURE MATTERS: ADVANCE CARE PLANNING SERVICE

What clients say...



- Service is excellent. Very helpful staff.
- Thanks Future Matters, for your very supportive and effective and efficient and friendly service. Greatly appreciated, feel more at ease.
- The service that Future Matters offers is very helpful, I never knew there was so much information out there to help my father in his future.
- I knew nothing about this service before so feel much more enlightened and able to signpost patients and friends/family to this excellent service.
- I've been able to discuss my Will wishes to my family and found Future Matters & Age UK have been very helpful every step in my Lasting Powers of Attorney application.
- Excellent service with follow up as they understand difficulties of following through with form filling etc. Great help with the process of Lasting Powers of Attorney. Very sensitive and caring and you don't feel rushed although you appreciate the urgency.

COMMUNICATION STRATEGY

Information sessions

The online and in-person information sessions are a key tool in raising awareness of the Future Matters Service, and are held every 2-3 months. The information sessions give an insight into various aspects of Advance Care Planning, LPAs, Funeral Planning and Wills.

Marketing channels

The information sessions are promoted together with the Death Cafés via a combination of digital mailings to **5K Age UK Islington clients** (with email consent), social media (Twitter, Instagram, Facebook and Linkedin), more recently within postal mailings to access those Age UK Islington clients without email addresses and additionally via Gentle Dusk's network.

Campaigns

Two campaigns during the year took place – the first a New Year campaign in January and the second in May for Dying Matters Week. The campaigns use the same marketing channels as for the information sessions, but content is also shared with nearly **800 Age UK Islington contacts from statutory and community organisations, including LBI and other communication partners.**

New Year campaign

The January campaign is designed to capitalise on the start of a new year being a time when people quite often have the time and energy to focus on organising their lives. It was promoted via the same channels as the information sessions.

The campaign offered the opportunity to call the Age UK Islington helpline to book an appointment with a Future Matters advisor about anything related to end of life planning. It was supported by a social media campaign featuring a variety of different people asking about different aspects of end of life planning.

The campaign was well received, with a good level of engagement and conversion into follow-up appointments to put plans in place.



Dying Matters campaign

The **Dying Matters 2022** campaign included promotions targeting Age UK Islington clients and wider Islington residents to attend online and in-person info-sharing sessions. Two interviews shared contrasting experiences of local people and the difference that planning ahead can make when a family member died suddenly.

Current Flyer

The flyer explains and promotes the FM service in easy to read dialogue for both Health Care Professionals for referrals and prospective clients.





HOW END-OF-LIFE PLAN CAN EASE SUFFERING FOR FAMILIES

Article featured in The Islington Tribune Friday, 6th May 2022 — By Charlotte Chambers.



Mireille Hayden with her father, Peter Herbert

A WOMAN who runs an organisation offering residents the chance to arrange end-of-life plans for free has urged people to come forward after watching her father suffer in his final years.

Mireille Hayden has called on people to contact Future Matters – currently only available to those who live in Islington or have an Islington-based GP – to sort out care plans, make treatment decisions and arrange wills, even if it is just for sentimental items not worth anything financially.

Ms Hayden said that had her father, Peter Herbert, made an end-of-life care plan it would have saved both of them a great deal of heartache before his death last year.

She spoke about the "traumatising" experience of watching him go from being a "bit absent-minded" to "being completely tipped into a world where words had no sense" after a bleed was discovered on his brain in September 2019. It transpired that he had had a series of strokes which had left him with just "half a brain" that was functioning.

She said: "He was admitted to hospital with a bleed, but instead of saying 'let's put him into palliative care', they tried to keep him alive. Keeping him alive was really unpleasant for him. It was prolonging his distress.

"I want people to listen to my story and make it a different story for the ones you love, and save them from the kind of distress I went through. The way to make changes is to put plans in place.

"My story is really traumatic but it doesn't need to be like that. If my father had written a plan for endof-life care he could have stated, 'If I become ill or lose capacity I want a natural death supported with palliative care'."

He was hospitalised and, not long after, all visits were stopped due to Covid. They did not see each other again for a year and a half.

Footnote: Peter Herbert died on 11 November 2021.

FUTURE MATTERS – OUR VISION FOR THE FUTURE

- FM volunteers will support clients to input their information and wishes into the forthcoming "patient portal" for the Universal Care Plan (UCP).
- FM volunteers will also be available to help GP Practices with the UCP as required.
- Expand the Future Matters service to other boroughs within London and across the UK.
- Independent evaluation of our Future Matters service.





Gentle Dusk works in partnership with Age UK Islington for the Future Matters Service in Islington

Learn more at: <u>www.gentledusk.org.uk</u> And: <u>www.ageuk.org.uk/islington/future-matters</u>

Special thanks to the team that made Future Matters a success for the 2022-23 period: Mireille Hayden, Judith King, Michael O'Dwyer, Maria Piroli, Katie Skea

And our amazing Future Matters volunteers: Alison, Caroline, Dorothy, Ellen, Helen, Julia, Juliana, Joanie, Joy, Maria and Pru.