

The Oxford Institute of

Population Ageing

A Review of Charitable Organisations Working With and For Older People in the United Kingdom

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Introduction

In recent years, there has been a growth in the number of organisations with an interest in older adults working with and for older adults in the United Kingdom, both nationally, regionally and locally. In addition, there has been a growth in the number of corporate bodies who see the commercial opportunities in ageing populations. The United Kingdom also has strong expertise in both the NGO and private sector as far as the provision of services and goods for older people and their families is concerned.

This report – the second of a series of five reports – will present an overview of key national organisations working with and for older people (directly or indirectly) in the United Kingdom. It will also include selected local organisations working in the field. This will be complemented by two international case studies.

The first report of the series explores the development over the latter half of the 20th century and up to the present day of the healthy ageing economy.

The third report will present a similar overview of key corporate organisations working with and for older people (directly or indirectly) in the United Kingdom as part of the direct healthy ageing economy.

The fourth report of the series presents a scoping and mapping of policy initiatives for older adults. This will comprise a review of relevant national government policies, enabling a synthesis of challenges, and possible solutions from the design world.

The fifth report will present the UN/WHO Age-friendly city initiative, with selected case studies from different continents.

The main methodology employed throughout has been desk research drawing on government documents, organisation publications and web resources. In a number of cases, key individuals have been invited to submit materials which have been utilised. Each report has extensively referenced all materials which have been sourced and used in the reports.

Contents

Introduction

1. Strengths in practice in the United Kingdom

2. Practice organisations for older adults

2.1 National level organisations

2.2 Local level organisations

2.3 International case studies

1. Strengths in practice in the United Kingdom

Does the United Kingdom have the capacity and capability to develop a leading ageing innovation industry? This would require a coming together of research and finance, policy and practice while at the same time investing in existing relevant areas of strength such as the design and creative industries in the UK. This is a standpoint supported elsewhere, for example in a 2018 report which states that *“the UK is an excellent position to achieve a global leadership position in the Longevity industry, so long as it focuses on the optimal assembly of its existing resources. It also highlights one of the strongest conclusions to come out of this report: namely that the British government should focus on and prioritize the coordinated development of its AI, Financial and Longevity industries, not separately but in synergetic convergence”*¹. But it goes on to say that *“What’s missing is a political decision to marshal these resources effectively”*.

As discussed in the first report of this series of four reports, the old age industry is not a new phenomenon, and in the UK as elsewhere, it has grown quite dramatically in recent years, focusing primarily but not exclusively on health technologies, which are clearly of a commercial nature. It is here that some concerns have been voiced by researchers and campaigners alike as to the drivers of this development²: are they the needs of the ageing population? Or are they simply the innovative capability of the developers which subsequently creates a market, thereby fulfilling its own statement of a need from the consumer? And as we have also noted in the first report, while health and care innovation is important, other dimensions such as work, homes, the public domain and social interaction are important – and it is at the intersection of these that true innovative practices need to be developed to ensure quality of life across the life course.

¹ Ageing Analytics Agency (2018) *Longevity Industry in UK*.

² da Silva Santana, C. & Leeson, G.W. (2015) Elderly Users’ Perspective on the Use of Technology in Daily Life: A Comparative Study of a sample in the UK and Brazil, *Iberoamerican Journal of Artificial Intelligence*, Vol.18 (55), pp. 35-49.

And while there may be an impressive catalogue of initiatives to address these various issues, it does seem that the field is fragmented rather than joined-up.

Let us move into this impressive field and begin by considering organisations working with and for older people, many of which work in the field of healthy ageing in one way or another, and some of which are investing significantly in innovative programmes. It is not the aim of this overview to provide an exhaustive catalogue of relevant organisations or corporates but rather to suggest how extensive the existing and potential work is in the UK (and elsewhere).

2. Practice organisations for older adults

In the first report, the example of Age Concern, now amalgamated with Help the Aged in Age UK, was presented to illustrate the development since the end of the 2nd World War of a major national organisation working with and for older people in the UK. Age UK itself comprises a collaborative network of local organisations under its national umbrella, and in addition there are other both national and regional and even local organisations with similar aims, some specifically for older people but others for a broader collection of age groups or specific diseases with special relevance to older people, for example Dementia UK.

Such organisations are often interest-based, focusing on a particular issue perhaps, such as housing with care (in its broadest sense), finance, loneliness, health, work/retirement, advocacy, and often they also have a campaigning dimension to their activities, attempting to influence policy at local and/or national level. Some may be more actively engaged in gathering evidence to support their cause, working in many cases with academics to provide the robust evidence-platform. As well as being part of the provision structure of the silver economy, they could also be avenues for provision (by others) by virtue of their extensive networks of and into older people and their families and their carers.

For ease of presentation, we shall present organisations at national level (though they may have regional member organisations) and separately at regional/local level (selected examples only). For national organisations, we shall mention their corporate partnerships, but this will be enlarged upon in the 3rd report of this series of reports.

2.1. National level organisations: the first report has already introduced Age UK by way of the development of such organisations in the UK, and this seems therefore like a good place to start a national overview.

Age UK: In 2009, Age Concern England and Help the Aged joined forces to create a new charity “dedicated to improving later life for everyone”, and a year later this new charity officially became Age UK. In order to continue the organisations’ international work, Age International was established in 2012, and this works to support vulnerable older people in over 40 countries globally. Today, this is a highly professional charity.

The organisation works at the national and local level with the support of its network, which comprises around 130 local Age UKs across much of England, and it also has longstanding collaboration with Age Cymru, Age NI and Age Scotland, all of which have similar structures and activities, so that its work, both in terms of support and campaigning, covers the whole of the UK. Age UK has an everyday presence in the lives of many of us by virtue of its 450 shops across the country, a business based on donations to the shops from the public and providing income to the local Age UKs. As a voluntary organisation as well, the organisation depends hugely on its more than 75,000 volunteers nationwide, who on a daily basis locally support older people in the community. As well as individuals, Age UK works with independent organisations locally across the whole country – called Friends – also providing a wide range of support services and activities such as visiting/befriending, dementia support, foot care, day care/day centres, transport, shopping services, IT training, cafes, social activities, exercise classes. Many of these Friends organisations are volunteer-led.

The Age UK advice line is a free, confidential national phone service for older people, their families, friends, carers and professionals providing or facilitating access to relevant advice, and in partnership with another charity, The Silver Line (see below), free telephone friendship services are available, providing a reassuring telephone chat on a regular or ad hoc basis.

Of particular interest in the context of this report is the more business-like dimension of Age UK's work, covering insurance, independent living, financial and legal services, and healthcare, and a variety of businesses partner with Age UK, tapping so to speak into the growing silver economy and promoting aspects of healthy ageing.

Tailored insurance is provided by Age Co to those aged 50 years and over and offers buildings insurance, contents insurance (or both), or car insurance, working with established insurance providers such as Ageas Retail, Call Assist and AXA. Age Co is the trading name of Age UK Enterprises Limited, a trading subsidiary company of Age UK, which donates its net profit to Age UK.

Age Co offers products and services to promote health and independent living, for example personal and fall alarms provided in collaboration with Taking Care; incontinence products provided in collaboration with Choice Shops; stair lifts and bathing adaptations provided in collaboration with Handicare Accessibility, which is part of the Handicare Group. Finally, Age Co offers financial and legal services in collaboration with Irwin Mitchell LLP.

Taking Care has over 30 years' experience of providing telecare and personal alarm services and it is part of AXA Health.

Choice Shops offers among other things healthcare retail services (incl. incontinence products).

Handicare offers solutions and support to increase the independence of the physically challenged and older people to enable them to live an independent, active life.

Irwin Mitchell LLP are legal and financial advisors founded in Sheffield in 1912.

Age UK also has a number of corporate partnerships, focused primarily on fundraising/financial support for the organisation. These include *Avis, ReAssure, Cadbury, Credit Suisse, Innocent, Santander, and Rothesay*.

Despite the fact that Age Concern and Help the Aged – perhaps the two best known charities working for older people in the UK – merged in 2009, the organisational space is still quite crowded. A second national organisation is Independent Age.

Independent Age: now known as Independent Age, the organisation can trace its roots back to 1863, when something called the United Kingdom Beneficent Association was established to prevent destitution by providing those in need (i.e. in poverty) with a modest but regular income. After a Royal Charter incorporation just before the 1st World War, the organisation was able to add Royal to its name and became the RUKBA. A report from the Nuffield Foundation in 1948 entitled *Old People* pointed out the need for residential care homes and the organisation opened its first residential home in consequence and began to focus its efforts on supporting older people, eventually changing its name to the catchier *Independent Age* in 2005 and broadening its web of support.

Services offered by the organisation to older people and their families are in many cases similar to those offered by Age UK and outlined above. For example, information and advisory services relating to care and support, financial matters, housing, health and mobility, along with friendship services provided by the organisation's volunteers to help combat loneliness amongst older people. The campaigning activities of Independent Age are often based on the evidence received through these services. Services can be provided on-line or in printed form.

Independent Age also works with a small number of corporate partners:

Firstly, *Fittleworth*, which works with the NHS and is a home-delivery medical equipment dispensary service for those with ostomy and urology conditions.

Secondly, the *Pension Insurance Corporation* which provides retirement income through comprehensive risk and asset and liability management.

Thirdly, the *3i Group plc* which is an international investment company with two complementary businesses in the fields of private equity and infrastructure.

And fourthly, *Cosy Club* is a bar and restaurant brand owned by Loungers plc.

Carers UK: Across the UK, it is estimated that almost 7 million people are carers of a loved one who is older, disabled or seriously ill (or any combination of these three), and for 30 years or more research shows that caring can have a huge impact on the lives of the carers in all manners of ways – socially, psychologically and financially, for example³. Carers UK is the UK's only national membership charity for carers, and it provides support and campaigns for change.

In 1965, the Reverend Mary Webster formed the National Council for the Single Woman and Her Dependents (NCSWD), and in 1988, this (renamed) organisation merged with the Association of Carers to create the Carers National Association. In 2001, the Carers National Association was relaunched as Carers UK

³ Leeson G.W. et al (1993) Family Care of the Older Elderly, European Foundation for the Improvement of Living and Working Conditions, WP No. WP/93/20/EN, Dublin.

Leeson, G.W. (2004) *Services for supporting family carers of elderly people in Europe: Characteristics, coverage and usage*, National Background Report for Denmark, Eurofamcare, University of Hamburg/European Commission, Hamburg.

Leeson, G.W. (2005) Changing Patterns of Contact with and Attitudes to the Family in Denmark, *Journal of Intergenerational Relationships*, Vol. 3 (3), pp. 25-45.

Del-Pino-Casado, R. et al (2019) The association between subjective caregiver burden and depressive symptoms in carers of older relatives: A systematic review and meta-analysis, *PLOS ONE* 14(5): e0217648, <https://doi.org/10.1371/journal.pone.0217648>; Zella, S. & Harper, S. (2019). The Impact of Life Course Employment and Domestic Duties on the Well-Being of Retired Women and the Social Protection Systems That Frame This, *Journal of Aging and Health*. <https://doi.org/10.1177/0898264318821205>.

establishing at the same time Carers Scotland, Carers Wales and Carers Northern Ireland in response to devolution. Over the years, the organisation has campaigned successfully to recognize and improve the rights and situation of carers across the UK. Today, the organisation provides telephone advice and support services, and through its carers' groups and more than 250 volunteers they reach out in local communities throughout the UK connecting carers with people who understand the challenges they face. The organisation's online community also provides a sharing platform.

The cited research⁴ reveals many of the challenges facing carers and Carers UK works closely with service providers in order to put in place the sort of support for carers to improve their own lives by enabling them to care more efficiently. This collaboration involves training for all types of health and social care workers to raise their awareness of the needs and rights of carers. Modern assistive and therapeutic technologies are becoming more and more mainstream in supporting older people and their carers⁵, and Carers UK works to disseminate information on the availability of these new technologies.

Around 3 million carers in the UK have to juggle their caring responsibilities with work and significant developments have been achieved in recent years to acknowledge this and to support carers in this situation⁶. In 2009, Carers UK launched an employers' membership forum which now has more than 210 member organisations across the public, private and voluntary sectors employing more than 3.5 million employees. With expert support from Carers UK, the aim of the forum is

⁴ Op.cit 67.

⁵ Petersen, A.S. (2017) *Posthuman Wellbeing*, Masters' Thesis, University of Aarhus, Denmark.

Leeson, C. (2016) *Anthropomorphic Robots on the Move; a Transformative Trajectory from Japan to Danish Healthcare*, Ph.D. Thesis, University of Copenhagen, Denmark.

⁶ Andersson, S. et al (2017) Information and communication technology mediated support for working carers of older family members: an integrative literature review, *International Journal of Care and Caring*, Vol. 1 (2), pp. 247-273

to enable employers to retain and support employees with caring responsibilities, a phenomenon dating back some decades in the form of so-called eldercare⁷.

Members of the forum are supported by Carers UK in various ways, from courses/events aimed at raising awareness of issues for carers in the workplace (and in their caring role), reviews of current practices in the member organisation, and supporting employees in respect of workplace and other supportive mechanisms, for example. Digital support services are also available for both the employer and employee. In addition, via Carers UK, member organisations are able to showcase their own carer support programmes. Membership fees for this Carers UK forum vary, based on size, public/corporate, and benefits available, with reduced rates for SMEs. Latest figures on the Carers UK website cite fees ranging from £1000 to £5000 per annum (this excludes SMEs). Within the structure of the forum, there is umbrella membership available – apparently to engage with more SMEs – for local authorities and for local employer organisations/business organisations.

Carers UK also operates a comprehensive so-called Carer Confident benchmarking scheme⁸ which helps employers to build a supportive and inclusive workplace for their employees who are, or may become, carers.

Of final interest for this report in respect of Carers UK and its activities is the fact that it invites businesses (and others) to enter into strategic partnerships based on a number of sponsorship opportunities designed to match the business objectives with the objectives of Carers UK – for example national campaigns. This would support the campaigning activities of Carers UK and (according to Carers UK) it would raise awareness of brands, promote positive PR and even “build emotional commitment”

⁷ Leeson, G.W. & Hoffmann, M. (1993) *Elder Care and Employment: Workplace Policies and Initiatives to Support Workers Who Are Carers*, European Foundation for the Improvement of Living and Working Conditions, Dublin.

⁸ [Carer Confident GUIDANCE Low-Res.pdf \(employersforcarers.org\)](#) and also the Carer Positive scheme operated by Carers Scotland for employers in Scotland, [carerpositive.org](#).

to the particular brand. Encouraging businesses to choose Carers UK as their charity of the year brings many of these dimensions together.

Embracing Age: a relatively new organisation, growing from a local community initiative to support older people in the community, Embracing Age is a Christian organisation founded in 2015 in the London Borough of Richmond upon Thames. The organisation's work in the community – dependent on an army of volunteers – is to combat loneliness, mobilise volunteers to work in the community, to equip community churches and to speak out on behalf of older people. The organisation has a number of designated activities, several of which have an element of Christian faith with opportunities for prayer, for any who would value this.

For example, "Care Home Friends" is a volunteer-based befriending service which targets residents in the community's care homes. The organisation has over 60 volunteers working across the care homes in the London Borough of Richmond, and is now expanding this work to for example, the Isle of Wight, Belfast, Liverpool, Hampshire, and Billingshurst. The support services include befriending, help to develop digital skills, and other general supportive activities. Care Home Friends in Richmond was a joint winner of the Cinnamon Project Lab in 2016.

The organisation also runs "Carers Together" which focuses its work on community informal carers for whom it aims to provide an on-line safe space to be able to find mutual support and encouragement. This started in January 2021 as a response to the Covid-19 pandemic to support informal carers who were increasingly isolated by the pandemic lockdown.

Also in response to the pandemic lockdown, the organisation launched its "Our Care Home Connections" project, which aims to enable care home residents to remain connected with their loved ones. The project utilises Alexa devices in an attempt to circumvent issues identified with the use of other methods of communication. This communication approach requires only a minimum of help from staff and enables

residents and family members to connect using voice enabled assistive technology. In Richmond, the organisation has provided 20 android tablets, which enable residents again to stay connected with family members, but with more help from staff.

The Silver Line: this is a multi-purpose help-line service for older people with a high public profile, down to its work but also its founder Dame Esther Rantzen, DBE. The Silver Line Helpline provides a confidential, free helpline for older people across the United Kingdom, and this service and support is available 24/7/365. The Telephone Friendship Service is offered in partnership with Age UK (see above) to people aged 60 and over who'd like to talk to someone on a regular basis. Basically, the organisation matches an individual with a volunteer for weekly chats over the telephone. The Silver Connect Service offers to help older people facing difficult situations and needing to connect with organisations and services in their local area to address these situations. This covers issues ranging from accessing benefits and social clubs and events, to health and social care issues as well help with housing-related issues. The help provided can be simply in the form of information or signposting, but it can also be help with actually contacting relevant services on behalf of the older person. These support services are provided by both staff and the Silver Line's team of volunteers, all of whom work from home and are distributed across the country.

The Silver Line partners with a number of support organisations in order to offer their contact/support services to distinct groups. For example, there is a partnership with the RAF Benevolent Fund. This partnership aims to facilitate group friendship telephone calls for up to six older people with links to the RAF. This typically applies to RAF veterans or the partner or widow(er) of an RAF veteran. Again, the calls are managed and co-ordinated by Silver Line volunteers. Along similar lines, the Seafarers Links facilitates these same group calls for people with a maritime background, for example former Merchant Navy, Royal Marines, Deep Sea Fisherman, retired Royal Navy, WRNS and RNA members, or anyone who has served

or worked at sea. The service is also available to spouses, partners, family members and carers with seafaring connections.

Over and above donations to support the work of Silver Line, the organisation arranges the usual type of fundraising activities, and in addition promotes corporate partnerships. These involve for example nominating Silver Line as the corporate's charity of the year, developing a marketing partnership, becoming a volunteering partner, or sponsoring an organisation event. In addition, the organisation has a scheme of lifelong recognition for the partners who supported Silver Line for the first two years after its launch. These so-called Founders include BT, Swiss Re, and Consultus Care and Nursing. Corporate partners include SAGA, Willis Towers Watson, HC One, BT, Annington, Royal London, Damart and others. These are all partnerships which support the work of the organisation financially.

Education and life-long learning is the focus of other organisations. We outline just two here as examples specifically focusing on older citizens.

The University of the Third Age U3A: this "movement" was started by Professor Pierre Vellas at the University of Toulouse in France in 1973, and has since developed into an international movement which aims to stimulate and provide education, mainly for members of the community in their third 'age' of life. The French model is linked into existing universities and has a strong element of learning. This was, however, modified when the concept was introduced to the United Kingdom in the early 1980s, where it was based on an understanding that the majority of retired people could and wanted to continue to contribute to society in a variety of ways – something borne out in the research⁹, and the focus of the U3A movement in the UK has therefore had no formal educational links but is based on bringing people together around a shared

⁹ Op.cit 1.

interest. In the United States, the comparable movement is linked more into life-long learning. In the UK, there are now more than 1000 U3A groups across the country with a total membership of around 500,000 (membership costs less than £20 per annum). The UK model is based on peer-based approach where members learning from each other, not to achieve a specific qualification but simply learning for pleasure. The movement operates on a purely voluntary basis.

The French model, with U3As having a university affiliation has been adopted across continental Europe. There is clearly a more formal educational component – often making use of university teaching staff. However, towards the end of the 20th century, the model in France widened to encompass all ages, becoming UTA (université tous âges).

In order to enable more people to participate in U3A activities, the Virtual University of the Third Age (vU3A) was launched at the beginning of 2009. This is open to all but in particular those unable to attend U3A meetings locally. The annual membership fee is currently £12. The whole system is also based on volunteers.

Today, there is a global organisation and network of U3As covering much of Europe, China, and Latin America.

In a similar vein, the *Ransackers Association* was established in 2010 to continue the work of the Ransackers Project, which began its educational activities at a number of colleges 2004 and continued until 2013. This original project engaged approximately 700 people aged 55 years and over to *return to study* and was founded in Oxford as part of the government's *Better Government for Older People* initiative, the basic idea being that older people who had not been to university could pursue a course of study as residential students for a ten-week term. This was not a formal course, but college academic staff supported them as they worked on a research topic with supervision, the use of computers and libraries, and the development of critical

thinking. The aim for the older student was to carry out a piece of research and submit a 5000-word dissertation. The courses folded in 2014 when the funding criteria for this sort of work changed and the colleges involved in the project could no longer sustain the courses financially. However, the Association has remained active, but in a different way altogether, focusing on research to support the basis for their original work with older people and education and the benefits derived from this.

Finally, we consider a number of national organisations (often with local or regional representation) working with and for older people (and their families) have a disease or disability as their main point of focus.

The first and perhaps most obvious one is

Dementia UK: Dementia refers to a set of progressive neurological disorders. Dementia affects older people and their families mainly, although some forms of dementia can develop at younger ages. Current estimates suggest that almost 900,000 people in the UK are suffering from a form of dementia¹⁰, and it is further estimated that this number will increase by 80 per cent to approximately 1.6 million by 2040.

Around 700,000 families in the UK care for people suffering from dementia¹¹. There is a longstanding and substantial body of research on the impact of caring on the informal carers¹², who in the UK alone provide an estimated almost £14 billion worth of unpaid care per annum¹³. In addition to these costs, there is a substantial economic

¹⁰ Wittenberg, R. et al (2019) *Projections of older people with dementia and costs of dementia care in the United Kingdom 2019-2040*, Care Policy and Evaluation Centre, London School of Economics and Political Science, CPEC Working Paper 5, London.

¹¹ <https://dementiacarers.org.uk/our-charity/who-we-are/>

¹² Brodaty, H. & Donkin, M. (2009) Family caregivers of people with dementia, *Dialogues Clin. Neurosci.*, Vol. 11(2), pp. 217–228.

¹³ <https://dementiacarers.org.uk/our-charity/who-we-are/>

cost associated with dementia estimated at almost £35 billion in 2019 (2015-prices), and increasing to a staggering £94 billion in 2040 (in constant 2015-prices)¹⁴.

Dementia UK is a charity which provides support for families with a member suffering from dementia. It receives no government funding. The charity's support services include specialist support via its dedicated so-called Admiral Nurses who work with people suffering from dementia and their families, providing one-to-one support, guidance and practical solutions to the challenging issues, which face these people. It also offers an Admiral Nurse Dementia Helpline (also an email service), where advice is available on symptoms and ways to address them and make them more manageable; on getting a diagnosis; on the different financial benefits available as a carer of someone suffering from dementia; on care homes, hospital stays or receiving help at home; on difficulties accessing care and support. Advice is available on a whole raft of issues, ranging from lasting power of attorney to employment and young onset dementia, but the main thrust is clearly around helping people understand dementia and the impact it has on individuals and families and how this impact can best be managed – issues such as changes in behaviour, maintaining health, but also the importance of carers looking after themselves and helping children understand dementia.

Dementia UK offers support and advice for those wishing to organise fundraising events to raise funds to support the work of the organisation. Corporate partnerships are important. For example, a three-year partnership with Central England Co-operative stores and colleagues have seen them raise funds and awareness across the region through a variety of fundraising activities such as sponsored walks, head shaves and Dementia UK 'Time for a Cuppa' bake sales. This partnership has resulted in £1.4 million being raised by employees and customers and from funds generated

¹⁴ Wittenberg, R. et al (2019) *Projections of older people with dementia and costs of dementia care in the United Kingdom 2019-2040*, Care Policy and Evaluation Centre, London School of Economics and Political Science, CPEC Working Paper 5, London.

through the stores' carrier bag levy charge. These funds have enabled Dementia UK to provide more specialist Admiral Nurse posts, training for Admiral Nurses and to run the Admiral Nurse Dementia Helpline. Another example is the partnership with the Zurich Community Trust, 2018 – 2021, which again helps fund an Admiral Nurse and the Helpline.

Dementia UK offers resources and support services to workplaces to help employees and customers live more positively with dementia and build a wider understanding of the condition. These resources and support cover awareness sessions for employees, and one-to-one confidential sessions for employees with a specialist dementia nurse. Part of this is also to enable staff to work with customers affected by dementia, including guidance for front line staff in branches, stores or call centres. An example is where Dementia UK's Clinical Services team has advised Assura PLC (a property business which designs, builds, invests in and manages General Practitioner and primary care buildings across the United Kingdom) on the design of a new primary care centre to ensure that the new building is accessible and navigable, comfortable to spend time in and a more inclusive environment for people living with dementia and their families.

Bespoke support is available to workplaces, covering direct access to the Admiral Nurse Dementia Helpline; advice to HR departments to enable the development of workplace support processes for staff caring for a family member with dementia; guidance sessions for managers to enable them to support their teams; collaboration with workplace carers networks; feedback on existing workplace well-being initiatives; and workplace planning for the future increases in people living with dementia. Such an example is Dementia UK's work with CABA (Chartered Accountants Benevolent Association) to ensure that former and current members of the Institute of Chartered Accountant community and their families have access to dementia specialist support. CABA is able to make direct referrals to the Admiral

Nurse Dementia Helpline. This complements any existing support measures offered by CABA to promote wellbeing.

The work of Dementia UK is promoted locally by a team of Volunteer Ambassadors who work alongside the Dementia UK Regional Fundraising teams to support people raising money in local areas, to identify new fundraising opportunities and to raise awareness of Admiral Nurses. It has a team of Dementia UK Ambassadors and Celebrity Supporters, among others the actors Jim Broadbent and Phyllis Logan. And an interesting innovative element of the organisation's work is its Lived Experience Advisory Panel (LEAP), established in 2017 and comprising both people living with dementia and family carers. LEAP provides feedback and advice and raises awareness locally of Admiral Nurses. The panel has advised and commented on the organisation's information resources, its surveys and its website.

Corporate partners involved in fundraising and financial support of the charity include *Leeds Building Society* and *Central England Co-operative*.

Founded in 2010, Dementia UK Trading Limited develops commercial opportunities and covenants its profits to the charity.

Two other dementia-related charities are Dementia Carers Count and Alzheimer's Society.

Dementia Carers Count: this charity was launched (as a renamed charity – see below) to support family carers of people with dementia, as well as the dementia and carer communities in the United Kingdom. Family carers need support in their role as a carer of someone with dementia, but they should also be recognised for the almost £12 billion they contribute annually to the economy. To provide this support, Dementia Carers Count responds to needs in a person-centred way, enabling carers to support not only the person with dementia but also themselves by building up their knowledge and resilience, based on evidence-based services and support from qualified professionals. New initiatives include a Dementia Carers Centre and the

creation of the UK's first dedicated Dementia Carers Count Professor of Family Care in Dementia at the University of Worcester.

But the organisation has a surprising history, given where it is and what it is doing today. It became known as *Dementia Carers Count* in 2018, but there is a rich history behind this 21st century name, stretching back nearly 160 years, when something called the Surgical Aid Society was founded in June 1862 by William Watson, a City lawyer, its aim to distribute medical and surgical aids to those in need – not just in the United Kingdom but across the world. After a number of early years with Royal patronage, the Society was granted the “Royal” title, something which today is retained by the Dementia Carers Count organisation.

In 1948, when the NHS was established and it became responsible for the provision of medical and surgical aids, the Society (as it was still known) changed its focus and set up care homes for older people and particularly those unable to pay for private nursing home care, acquiring in 1951 two homes which initially were more like hotels than care homes, providing accommodation and companionship. Over time, residents were, however, becoming older and frailer and the Society had to change to meet these changing needs, and with time the number of homes increased. The Society also decided to become a “repository of good practice” in the field of (dementia) care and by the turn of the 21st century had developed into an acknowledged leader in the provision of care for older people and those suffering from the diseases of old age. In 2012, the 150th anniversary of the organisation, it was decided again to refocus its work, this time to support family carers of people with dementia, and just a few years later the new name, Dementia Carers Count, was chosen to reflect this new mission and purpose, which is about recognising the challenges faced by carers of family members suffering from dementia and providing help and support across a variety of issues to these carers. This includes the provision of free courses designed and delivered by healthcare professionals to enable carers to develop the skills and confidence required to cope with the challenges of the care task and thereby helping

them to maintain their health and well-being. The organisation also brings dementia carers together to share experiences and to share the burdens of car. A variety of courses are provided, from short (between 1 and 1.5 hours) on-line courses for small groups to three-day courses, all designed to address the needs of carers in very different situations. One-day courses cover specialised subjects in greater depth, such as eating, drinking and swallowing difficulties, feeling secure in relationships, communicating with someone with dementia and sudden or extreme confusion. These courses are designed and delivered by expert healthcare professionals who have experience of supporting people with dementia and their families. The courses are free of charge but participants or their employers are invited to donate to the charity on completion of the course.

As with many of the organisations considered in this report, Dementia Carers Count relies heavily on its Ambassadors to spread the word about the work of the organisation so that family carers of people with dementia become aware of and can access the organisation's services. Ambassadors also take part in fund-raising events and other events designed to increase awareness of the organisation.

Dementia Carers Count understands the benefits of collaborative partnerships with companies (for example *Aviva*), trusts (for example, *Albert Hunt Trust*, *Childwick Trust*, *Linbury Trust*) and foundations and philanthropists and therefore develops this in a number of ways – again similar to the way in which other charities in the field work, but with an emphasis on the carer encouraging employers. For example, persuading an employer to nominate the charity as its Charity of the Year, which would then lead to a host of fundraising activities by the workplace/employees. Or to initiate a Payroll Giving scheme.

Alzheimer's Society: founded in 1979, Alzheimer's Society is one of the leading dementia charities in the United Kingdom. By 1983, the Society had started funding research projects and fellowships, and in that same year Regional Development Offices were opened in nine areas – their aims: to establish relatives' groups which

would provide practical and social support; to contact local government and agencies to ensure better understanding of and provision for people with Alzheimer's; and to raise public awareness of dementia. In 1989 – the Society's 10th anniversary - the first ever Dementia Awareness Week was held and just one year later the Society had attained a membership of 10,000. The Society's focus on research has remained strong throughout, and 10 years after its first round of funding it launched a £1.25 million programme of funding for Post-Doctoral Research Fellowships.

In 1994, in addition to its existing activities, the Society began its learning programmes. There was an open learning programme for people to study in their own time, including a carer's resource pack aimed at new carers of people with dementia, and the care workers course to encourage good practice in care homes. Also by the mid-1990s, the Society was expanding its political activities, and in 1996 *Challenging Dementia*, its first general election manifesto, was produced.

Another milestone appeared in 1998 when the well-known TV presenter Anne Robinson launched the Society's National Dementia Helpline, which received more than 20,000 calls in its first year. In the same year, the Society's website was launched to provide easily accessible information about dementia, the availability of help for carers, details of press releases, news of events and information about the work and support services of the Society.

In 1999, 20 years after its inception, the Society became known simply as the Alzheimer's Society and the Government issued a National Strategy for Carers in response to the calls from a number of charities.

The 30th anniversary of the Society in 2009 saw the launch of the Dementia Advisor service. This would provide information, signposting and support in communities in response to the needs of people with dementia and their carers, and in 2012, as well as contributing to the Prime Minister's *Challenge on Dementia*, the Society pronounced its own five year strategy, *Delivering on Dementia*, aiming to demonstrate the way in

dementia care and support; be the first point of contact for anyone dealing with dementia; lead partnerships and investments in research to improve care, advance prevention, and move closer to a cure; and campaign for people affected by dementia to be able to live the lives they want. By 2015, the Dementia Friends programme had reached its target of 1 million dementia friends – after just 2 years, and in 2016 actor Carey Mulligan became Global Dementia Friends’ Ambassador for the United Kingdom.

In 2017, the Society’s income reached more than £100 million, and 1 year later 17 insurance industry leaders pledged to raise £10 million for the Society, and the number of Dementia Friends exceeded 2.5 million by the end of that same year. The varied activities of the Society were such that the number of interactions with people affected by dementia was in excess of 6.5 million. In addition, its almost 3,000 local services were helping more than 100,000 people, while another 42,000 people were supported by the Society’s Helpline (open 7 days a week providing information, advice and emotional support), 60,000 gained support by joining Talking Point (an online community to pose questions, share experiences and get information and practical tips on living with dementia; free 24 hours a day access) and the website attracted 11 million views.

Today, the Society continues to campaign for change, fund research and support people living with dementia, with the strategic objective to offer support to all people newly diagnosed with dementia by 2022.

The Dementia Connect service was initiated in 2018 to transform the support provided to each individual person, combining face-to-face support with telephone and online advice and information offered by specially trained Dementia Advisers. These Dementia Advisers and other trained volunteers help people with dementia take back control of their lives and remain independent for longer. As part of Dementia Connect, the Society’s Side by Side volunteers support people with dementia to remain active in their communities.

The Society offers a variety of dementia programmes ranging from personal choice programmes to carer information and support programmes, from dementia voice programmes to external training programmes, all of which target people suffering from dementia and their carers, with the external training programmes aimed at staff and volunteers in the social care and third sector, the health care, statutory and housing sector, and the private sector.

In addition, the Society campaigns politically at all levels and continues to support research.

Corporate partnerships are an important aspect of the Society's work, and include *Cadent* (the largest gas distribution network in the United Kingdom), the *NatWest Group* and *Compass Group UK and Ireland's Healthcare Retail* sector.

A number of charities while not having older people per se as their main focus will indirectly be working with and for older people and their families. One of these is *Headway – the brain injury association*, the UK-wide charity that works to improve life after brain injury by providing vital support and information services. The charity also lobbies for better support and resources to be made available to people affected by brain injury and works to raise awareness of brain injury and the devastating effects it can have. There is a network of Headway groups and branches across the United Kingdom and the Channel Islands. The charity's primary mission is to promote a better understanding of brain injury and its impacts and to provide information, support and services to those with brain injuries, their families and their carers, but it also campaigns to address the causes of brain injury and thereby to reduce the incidence of brain injury, supporting and establishing so-called Headway Groups across the United Kingdom to address the needs of all sections of the community.

The history of the charity is closely linked to advances neurosurgery which, in the 1970s experienced dramatic developments which enabled more and more people with serious head injuries to survive these injuries. However, these positive developments in neurosurgery were not accompanied by equally positive developments in the funding of rehabilitation and community-based care services. As a result, people who had suffered severe head injuries were discharged into the care of unprepared families or into the care of inadequate and inappropriate institutions.

Headway was effectively born out of personal need, when in 1979 Sir Neville Butterworth was seeking holiday accommodation for his brain-injured son. The contacts thus made and the support networks uncovered basically led to the establishment of *Headway* in late 1979 and it was registered as a charity in March 1980. The lack of long-term rehabilitation facilities, respite care and hospital liaison led to the first Headway House opening just three years later, and its success led to other Houses opening across the United Kingdom. Today, there are more than 125 Headway groups and branches throughout the United Kingdom working to support people in their local communities and raising funds locally level to be able to continue their support services.

In 1999, the charity's work was extended to include support for people suffering from other forms of acquired brain injury (e.g. meningitis), and as the charity has grown in size, so too has its role in shaping brain injury services, and in 2001, the charity's name was changed to *Headway - the brain injury association*.

A national helpline was launched in 2003 and the first charity shop was opened that same year. The helpline receives around 9000 enquiries a year, and there are now 28 charity shops, which as well as generating income also increase awareness of the support work of the charity.

A number of relatively recent key support initiatives are worth mentioning:

the Headway Approved Provider scheme helps families identify residential care units that provide high-quality specialist care and support;

the Headway Emergency Fund helps families and individuals cope with the practical implications of a sudden major brain injury;

the Headway Acute Trauma Support nurses provide crucial support to families in the vital early stages following injury.

In addition to individual or group donations (from fundraising activities), corporate support is an important part of the charity's work to raise funds for its many services, and much like other charities considered in this overview, Headway offers a range of opportunities for corporates and other organisation to support the work of the charity, for example: adopt Headway as charity of the year; exhibit at the charity's conferences; advertising in the charity's quarterly magazine; supporting the charity's annual awards luncheon; payroll giving; paying for the cost of running the helpline (approximately £600 per day); participating in Headway's annual corporate adventure; participating in *Hike for Headway* (bespoke guided hikes for employees) or wellbeing walks. Corporate membership is also available, with rates of membership depending on the size (number of employees) of the organisation (currently from around £400 to £800 per annum). Membership benefits include discounted rates on conference participation and magazine advertising, for example. Partners include Aldermore Bank, Old Square Chambers and Home Care Preferred.

Parkinson's UK: The beginnings of the charity go back to 1969 when Mali Jenkins founded what was then named the Parkinson's Disease Society, based very much on her personal familial experience and needs. The newly formed Society had three main aims: to help patients and their relatives with the problems arising from Parkinson's; to collect and disseminate information on Parkinson's; and to encourage and provide funds for research into Parkinson's. In many ways, over 50 years on, not a lot has changed in terms of the charity's mission, as it still focuses on three areas of

importance to people with Parkinson's disease, namely accelerating breakthroughs in research, providing better support every day, and raising awareness and improving understanding of the disease.

1970 saw the establishment of the Society's first two local Parkinson's groups in Tunbridge Wells and Halifax respectively. Today, there are more than 360 such local groups across the United Kingdom offering friendship and support to those affected by Parkinson's. The next decade saw the establishment of the Parkinson's Brain Bank which would enable vital research into the disease, allowing researchers to identify the key parameters in Parkinson's, and by the end of the 1980s the first specialist Parkinson's nurse had been appointed, providing specialised local care for people with Parkinson's. Today, there are more than 300 of these specialised nurses across the United Kingdom. The end of the 1990s saw the charity publish its first education tool for professionals and that has developed to the stage where the charity today delivers education courses for health and social care professionals across the United Kingdom, and soon after this in 1999, the charity's helpline was launched with specialist nurses and advisers providing advice and support to those affected by Parkinson's.

As research into Parkinson's increased, so did the funding, and by 2007 the charity's research spend amounted to more than £4 million – in 1969 when the original Society had been founded this spend had been a more modest £200. As the first decade of the 21st century drew to a close, the charity's online discussion forum was launched as were what are now called local advisers to enable those affected by Parkinson's to access the services they needed. Having marked its 40th anniversary, the Society as it still was changed its name to Parkinson's UK in 2010 and launched a 5-year strategy focused on finding a cure and improving life for those affected by the disease. Critical research continued and in 2012, the largest ever in-depth study of people with Parkinson's was launched by the charity. A programme was developed to train volunteers – themselves affected by Parkinson's – to support others to cope with

Parkinson's. And 2017 saw the establishment of Virtual Biotech, the charity's drug development arm.

Not surprisingly, Parkinson's UK has a comprehensive portfolio of corporate partnerships which support its work in a variety of ways in line with the sorts of partnership arrangements seen elsewhere in the charities presented in this overview. Selected recent examples of corporate partnerships are:

The *National Garden Scheme* which facilitates every year the opening of almost 4000 gardens to the public in England and Wales; the international consultancy and construction company *Mace*; the independent family owned and operated company *Paydens Pharmacies*; the recruitment service *Annapurna Recruitment*; the *Association for Public Service Excellence (APSE)* - a not-for-profit organisation dedicated to promoting excellence in the delivery of services to local communities; *Stannah* (a well-respected designer and manufacturer of stairlifts) and *Symprove*, a unique water-based bacteria supplement, working to support the microbiome in the gut.

AbilityNet: the organisation was created in 1998 by IBM and Microsoft to share technological solutions for disabled people. The organisation supports people of all ages, living with any disability or impairment, to use technology "to achieve their goals at home, at work and in education". They do this by providing specialist advice services, free information resources and by helping to build a more accessible digital world. In addition to working with individuals, the organisation works with businesses, universities, charities and other organisations to design and maintain accessible websites, apps and other digital services.

Services are offered to students, disabled people and their carers, and to older people, offering free resources such as webinars, factsheets, blogs and videos as well as one-to-one advice. The *My Computer My Way* initiative is a guide to the adjustments that make computers, laptops, tablets and smartphones easier to use.

AbilityNet utilises a network of volunteers with IT skills to offer free computer and technology support to older people and people with disabilities of any age, ranging from help with computer viruses, installation of broadband or updates to choice and installation of hardware and software as well as assistive technologies. Service can be provided over the phone or the internet (and at home pre-Covid).

Microsoft and *IBM* are corporate supporters of Ability Net.

VOICE (Valuing Our Intellectual Capital and Experience): this organisation works to drive innovation for ageing and improve health research. It comprises a large network of citizens across the United Kingdom as well as internationally, who provide insights, experience, ideas and vision to identify unmet needs and opportunities. VOICE is part of the National Innovation Centre for Ageing (NICA). Based at Newcastle University, NICA co-develops and brings to market products and services designed to create a world in all citizens live longer, better lives. It brings together multidisciplinary professionals and researchers, commercialisation experts, scientists, innovators, and technologists working closely with the public, exchanging their intelligence. The two organisations together have developed something called *Ageing Intelligence*, which harnesses and utilises the experience, wisdom, skills, insights and expertise of citizens of all ages and backgrounds, together with key stakeholders. NICA offers (free) *Ageing for Innovators* courses which are designed for those with an interest in ageing and how it affects individuals and businesses and the opportunities for innovation.

VOICE also supports researchers with regard to patient and public involvement. It provides a community of patients, carers and members of the public who contribute their own *lived experience* to identify priorities and unmet needs and are involved in all stages of the research cycle.

They work with Newcastle University, Imperial College, NIHR Clinical Research Network North East and Northumbria, the Dementia Innovation Hub, the NIHR Innovation Observatory, the Amazing Community and Bournemouth University.

A number of smaller, perhaps less well known niche organisations are also worthy of mention in this overview. For example:

Contact the elderly addresses loneliness in people aged over 75 years who are living on their own. The idea is based on volunteer-led tea party groups which take place in volunteer hosts homes. The organisation's drivers collect guests from their homes. Over 770 groups take place one Sunday a month throughout the United Kingdom.

Contact the Elderly have been successfully organising such tea party groups for almost 60 years. Tea party groups have a demonstrably beneficial impact on older individuals giving them something to look forward to and enabling them to develop friendships and enjoy the company of others, providing social interaction and increased self-worth.

The Cinnamon Trust is the only specialist national charity working to relieve the anxieties and problems faced by older and terminally ill people and their pets. The Trust was founded in 1985 and its main aim is to help retain the relationship between pets and their (older) owners, utilising a network across the United Kingdom of more than 17,000 volunteers who provide practical help with day-to-day care should the need arise (for example, walking dogs, fostering dogs on a short term basis in the event of hospitalisation or being housebound). Long-term pet care is also available if the owner dies or has to move into residential care.

The Trust provides advice and information on pet-friendly care homes, and has set up a Pet-Friendly Care Home Register. The Trust's volunteers help older owners to visit care homes they may be considering, and the Trust helps homes to become (more) pet-friendly.

The Elderly Accommodation Counsel is a national charity that aims to help in various ways older people (and their carers/families) make informed choices about their housing and care needs. It was founded in 1984, and became registered as a charity in 1985. The Counsel has worked with a two-pronged approach since it was founded.

Firstly, it provides information and advice directly to older people, their families and their carers, and secondly, it works to raise awareness amongst advisory agencies, professionals and policy makers of the importance of relevant information and advice to enable people to make their own decisions about how and where they wish to live as they grow older and perhaps become more dependent. In 2008, the Counsel built on its success of the first 20 years to introduce *FirstStop*, a comprehensive information and advice service covering care, housing and associated financial matters in collaboration with Age UK, among others. *FirstStop* has developed into the main vehicle for the Counsel to live up its mission, with all other activities designed to support *FirstStop*.

The major funders of the Counsel's work in recent years have been the Big Lottery Fund, the Department for Communities and Local Government, Comic Relief, and the Nationwide Building Society. The counsel was put in charge of funding and managing local service delivery programmes on behalf of the Department for Communities and Local Government. This enabled the organisation to develop partnerships with more than 40 local organisations, leading to *Housing Options for Older People* – an online service in partnership with local authorities and others.

Housingcare.org is an online service providing information on care, support and housing for older people. This contains a directory of around 25,000 specialist housing developments and around 12,000 care homes.

Relatives and Residents Association is a national charity, founded in 1992 as the *Relatives Association*, for older people in need of care and their family and friends, who form the supportive network of the older person. When it was formed, the idea was that the Association would help relatives and friends to work with care homes to ensure the highest possible quality of life for all older residents. It was renamed *The Relatives & Residents Association* in 1998 to emphasize the broader scope of its work. Today, the Association is recognized as an independent voice working for higher

standards together with charitable foundations, academic institutions and a range of organisations which provide services for older people.

The Association's free Helpline provides information, advice and support to older people and their families/friends, and it also uses the experiences of older people and their families/friends to raise awareness and to influence policy and practice. If helpline staff are unable to resolve issues and/or a greater level of support is required, in-depth services are available.

The Corporate Membership scheme entails working in partnership with care services, encouraging provider organisations and individual homes to improve the care they deliver. Corporate members receive, for example, information resources, a corporate membership network to share best practice, access to regular analysis and commentary on news and developments in social care, and Association publications at reduced rates.

Friends of the Elderly was founded in 1905 as The Church Army League of Friends of the Poor. As *Friends of the Poor* it became an independent organisation in 1911, and in 1972 the name was changed to *Friends of the Elderly*. These changes themselves represent the organisation's attempts to respond to the changing needs of people and society. Individual grants were first introduced in 1905. Immediately after the Great War, the organisation set up so-called *Penny Dinners* in the poorest districts of London and helped men to get work, back pay and pensions as they came home from the war.

The need for the sort of support offered by the organisation increased during the Second World War, and by 1945, work had begun to focus on frail and older people. As the number of older people requiring nursing care increased throughout the 1960s, the organisation added nursing wings to its residential homes and introduced efforts to support older people in their own homes or in other nursing homes.

The Friends of the Elderly Group offers community services to support people to remain living independently in their own homes and in addition, its care homes provide residential, nursing and specialist dementia care. Reducing loneliness is also a priority and the organisation provides a range of volunteer led activities and services. For those on a low income, grants are still available (and have been since 1905) to help older people meet unexpected costs and to stay connected with their communities.

Some organisations have tackling loneliness in old age as one of their priorities and other organisations have it as their main priority. For example, *Re-engage* is an organisation with national office in London and teams across the United Kingdom. It began in 1965, very much as a personal response to an encounter with an older woman's loneliness in London. In September of that year, the organisation – then called *Contact* – was granted charitable status and within a few years had changed its name to *Contact the Elderly*, settling on its current name in 2019.

Today, the charity helps almost 10,000 lonely and isolated older people. Almost 1000 social gatherings are arranged annually, supported by 14,000 volunteers, providing social connections for lonely older people. This is based on monthly Sunday tea parties in the homes of volunteers. During the Covid-19 pandemic, these physical gatherings have been replaced by a telephone befriending service based on *call companions*, a service which will be continued alongside the physical gatherings when some sort of normal returns to everyday life.

An interesting objective of the charity is to encourage younger people to devote time to the work of the charity in their local communities. In addition, it is hoped that *Re-engage* can be developed into an intergenerational community in a bid to tackle ageism.

Again, we see corporate partnerships as a crucial dimension, enabling and raising awareness as well as fundraising. Recent corporate partners have included Prezzo and Knight Frank.

The final national organisation working with and for (a specific group of) older people in this overview is *Hourglass*, which is the only charity in the United Kingdom focusing on the abuse and neglect of older people, something which it is estimated affects almost one fifth of older people in the country. The charity's mission is to end the harm, abuse and exploitation of older people in the United Kingdom. Founded almost 30 years ago as *Action on Elder Abuse*, the organisation has helped thousands of people, helped shape government policy and helped raise awareness of the issue of elder abuse. The charity runs a free helpline for older people and their families suffering from physical, financial, sexual or psychological abuse as well as neglect. To achieve its goals, *Hourglass* collaborates with key stakeholders, creating programmes to change lives and attitudes. This involves creating safe environments to prevent the abuse and neglect of older people, but it also involves empowering older people.

In 2015, the charity launched EARS (The Elder Abuse Recovery Service), a programme to support older victims of abuse to recover from their experience, regain confidence, and re-integrate into their local communities. Older victims were matched with local volunteers who supported them during their recovery. From 2021, EARS has been embedded in the charity's Community response programme, which continues to support older people with their recovery from abuse. Long-term plans are to provide Community Hubs across the UK and Ireland. This programme retains the volunteer-led support model as part of a reshaped and much wider offer of support.

In recent years, the charity has enjoyed corporate partnerships with *Simplyhealth* (affordable health care providers), *SureSafe Alarms* (providers of telealarms and personal alarms), and *Hodge* (later life lenders).

To complete this national overview (by no means exhaustive), it is pertinent to present the work of a voluntary organisation working broadly across the United Kingdom with a huge variety of issues, namely the *Royal Voluntary Service*. Founded in 1938 as the Women's Voluntary Services for Air Raid Precautions, the organisation has inspired around two million women and men to volunteer their time to help others, making the Royal Voluntary Service the largest volunteering organisation in British history. By 1943, the organisation had more than one million volunteers involved in almost every aspect of wartime life.

Post-war, the Service became a leading organisation in the field of social care, pioneering the practices that formed the cornerstone of modern social services, and in recognition of the service WVS and its volunteers had given to the country, in 1966 Her Majesty the Queen granted the use of 'Royal' in the organisation's title, becoming then the Women's Royal Voluntary Service, finally renaming itself as the Royal Voluntary Service in 2013. Today, the thousands of volunteers helping to make communities stronger, for example providing support for older people to remain active.

As part of the Service's Community Companions and One-to-One Support services, these volunteers drop in regularly just for a chat over a cup of tea or perhaps to pick up people who are unable to get to their GP, to hospital appointments or to the local shops, for example, as part of the Service's Community Transport scheme. The Home Library Service sees volunteers deliver books to the home of those no longer able to get to the local library.

The Service has a Community Dementia Support programme to help individuals live healthily and happily, and continue to do the things they enjoy and remain involved in their community. In addition, there is a Dementia Support on Ward scheme which aims to provide some comfort and structure to an individual suffering from dementia during a hospital stay. Individuals with mild to moderate dementia can access dedicated volunteer support and Cognitive Stimulation Therapy programmes

throughout a hospital stay, which can include reminiscence activity or provide company and reassurance when a patient needs to attend a clinic or X-ray away from the ward.

Of course, the Service has numerous corporate partnerships to support its work, for example Admiral (insurance), Legal & General, Specsavers and W. H. Smith, amongst others.

2.2. Local level organisations: there is a multitude of local organisations working with and for older people in the United Kingdom. Often, these are local branches of (some of) the national organisations discussed in the previous section.

It is clearly way beyond the scope of this report to provide anything like a comprehensive review of these organisations. Therefore, in the following, we mention but a few to give a taste of the wealth of activities and services being offered to older people and their families locally.

Thrive: Thrive is a small (national) charity that uses gardening to change the lives of disabled and older people. Thrive has two local gardening projects, one near Reading in Berkshire and one in Battersea Park, South London. In addition, Thrive supports around 900 gardening projects in England and the Irish Republic.

Ageing Better in Camden: this is a partnership of older people and more than 20 organisations in Camden. The partnership works to tackle social isolation and loneliness among older people, and the diverse group of partners ranges from Age UK Camden to the Seethrough Theatre Company, from the BAME Community Action project to LGBT+Connect – Opening Doors London, and many more. This is one of the fourteen National Lottery Community Fund Ageing Better programmes across England.

Age UK Enfield: this is a local charity that has been working in the community for around 30 years to support older people, their families and their carers. Trained advisors offer free information and advice to older people and their families. home

support services help with shopping and cleaning. Regular exercise classes under the Fit for Life programme are run at various venues across the borough, and the day centre has a wide range of activity groups and events to give older people the opportunity to keep fit, socialise, or learn a new skill.

Bristol Older People's Forum: the Forum was established in 1933 and has around 3000 members aged 55 years and over. It provides a platform for older people to participate actively in the community, to influence policy and decision-making, to challenge ageism and to promote Bristol as part of the UN/WHO Age-Friendly City Network. The Forum works in partnership with other organisations including The Care Forum (lead partner in the Voice and Influence Partnership), The Bristol City Council, Bristol Ageing Better, Age UK Bristol, St Monica Trust, LinkAge Network, John James Bristol Foundation and the Bristol Dementia Action Alliance, and works on a number of projects including the Housing Action project, the Transport Action Project and Challenging Ageism Workshops. **here**

Cymru Older People's Alliance: is an independent, representative, national organisation run by older people for the benefit of older people in Wales. Its objective is to enable older people across Wales to have an independent voice which ensures that older people's opinions are heard, acknowledged and acted upon. It aims to achieve this objective in a variety of ways, for example working in partnership with older people's organisations across Wales to create a collective voice and working in partnership where appropriate, with Government, statutory, voluntary and public organisations. The Alliance's membership structure includes each of the 22 Local Authority Older People's Forum or Group – each elects two members to the Alliance. Currently, 17 Forums are represented in the Alliance. The Alliance published a manifesto in 2019 outlining the most important policy areas it believes need to be addressed by Governments at all levels.

The Scottish Pensioners' Forum: this was established in 1992 as an umbrella organisation for groups and individuals working and campaigning for a better deal

for older people in Scotland after discussion with bodies such as Help the Aged, Age Concern and the Scottish Old Age Pensions Association. The Forum is a non-profit organisation managed by an Executive Committee, elected each year at the Annual Conference. Members of the Committee give their time voluntarily and represent Regional Elderly Forums, Churches, Trades Unions, Ethnic Minorities. There are also individual members of the Committee.

Scottish Older People's Assembly: The Scottish Older People's Assembly aims to enable older people in Scotland to share their challenges and concerns, but also to celebrate the positive contribution that older people make to society. The Assembly comprises more than 50 membership organisations ranging from community groups to campaign organisations, from equality and minority groups to lifelong learning associations. Individuals can also become members. The Assembly arranges national assemblies (nine since 2009) and local meetings to influence decision makers, and they work on issues such as fuel poverty, housing, transport,

Age NI: Age NI (member of the Age UK family) is the leading charity for older people in Northern Ireland, and many of its aims and visions reflect those of Age UK. The charity provides a range of services across Northern Ireland including advice services, day centres, residential care facilities and home care services, emotional and practical help at a time of crisis, support to remain active in the community, and support for older people suffering from dementia and their families (carers).

Age NI provides products (and services) designed specifically for older people. These include personal alarms, a range of insurance products for those aged 50 years and over, funeral plans, bathroom and mobility aids, and a range of charity shops.

The charity has a number of corporate partnerships, which provide financial support. These include First Trust (banking), Power NI, Santander, and Ulster Chemists' Association.

2.3. *International case studies:* the development of organisations working with and for older people is not unique to the United Kingdom. As welfare states developed and as population ageing manifested itself at an individual and community level, organisations developed to address the issues of ageing, to campaign for the rights of older people, and to engage with older people with regard to remaining active and healthy.

In this section, we shall consider just two organisations outside the United Kingdom, one in Europe and one in North America. This is not because these two organisations are necessarily standard bearers or examples of good practice, but simply because they serve as a useful comparison to the organisations otherwise presented in this overview.

Just as the organisations in the United Kingdom reflect and are products of the development of the welfare state in the United Kingdom, the same is true of our two international case studies.

Let us begin close to home, in Europe.

Through the 1980s and 1990s in particular, and continuing to the present day, older people's organisations across Europe were working predominantly at national level, but moves were taking shape to organise these organisations at the European (and even at the International) level. Today, *Age Platform*, based in Bruxelles, works to promote older people's rights and interests in Europe, working with both EU and non-EU bodies, but most interesting in the context of this report is the fact that the Age Platform membership comprises just over 100 organisations (a combination of older people's organisations, research organisations, policy centres at national and European level). According to the Platform's own membership directory, six of these more than 100 members are from the United Kingdom – none of these is included in this overview report. Two of them are research/policy units, namely the British Society of Gerontology and the International Longevity Centre UK. The remaining four

members are the Older Women's Network Europe, Wise Age Ltd., Homeshare International, and the Civil Service Pensioners Alliance.

One of the Platform's current members is the DaneAge Association. The Association has a history of working in Europe since its foundation in 1986, having been a founding member of EPSO (European Platform of Seniors' Organisations), which later become one of the initial members of the Platform. At the time, it's mother foundation, DaneAge Foundation, was a member of EurolinkAge, which also later become one of the initial members of the Platform. In European – and even international – terms, DaneAge is unique and it is therefore an obvious and pertinent choice of one of this report's two international case studies.

DaneAge Association: almost paradoxically, the origins of the modern DaneAge can be traced back in many ways to the late 19th/early 20th century and the initial introduction of the early signs of the welfare state, which would then roll out across Europe in various forms and to various degrees. Welcome as they undoubtedly were, pension systems introduced a marginalised social space for older people – these benefits' systems defined (and continue to do so) an exact age, beyond which citizens become defined and regarded as dependent, separated from the other productive section of the population. As a result, a well-defined phase of life called old age becomes anchored in society's judicial and administrative structure. It was around this time that civil society organisations working for older (poor disadvantaged) people began to appear.

So for example, in Denmark, the Copenhagen priest Hermann Koch established an organisation called EGV (Eensomme Gamles Værn – Association for the Protection of Lonely Old People) in 1910. He was one of the first to draw attention to the existence and need of poor older people. It happened at a time when it was difficult to be old if you did not have close family with resources to take care of you. Koch's first initiative was to arrange "student collections for poor people's Christmas", where he was able to marshal help from Copenhagen university students. This was a success and EGV

was then in a position to collect funds on a regular basis to establish activities for these lonely, poor older people – for example, a rural retreat where poor old people from Copenhagen could take a summer break outside the city. And just 1 year after its foundation, in 1911 EGV set up its first old people's home in Copenhagen. More were to follow.

Right up until the outbreak of the 2nd World War (and the occupation of Denmark), the not-for-profit EGV arranged drop-in day centres for more than 3000 older people every week providing social interaction and entertainments. By the 1970s, the organisation had grown into a provider of day centres, residential care facilities and collective dwellings for older people across the country and as such was a major player in the provision of these care and support facilities for older people in what was a fast-growing welfare state. EGV worked closely with local councils and as well as employing several thousand professional staff also drew on the contribution of a similar number of volunteers. It remained a private, not-for-profit organisation and developed other activities – for example, building contractors for as well as the managers of day centres, care homes and specialised housing for older people, but also a travel bureau specifically for older citizens. Local councils with whom the organisation worked in partnership have since taken over ownership and management of what used to be EGV's centres and care homes. Today, renamed the Foundation Ensomme Gamles Værn, the organisation focuses on supporting humanitarian research (for example older homeless people¹⁵) along with social initiatives such as tackling loneliness and marginalisation of older people in Denmark.

In 1984, EGV appointed a new dynamic Chief Executive Officer, Bjarne Hastrup, to develop the organisation, and in 1985, its 75th anniversary, EGV decided to support the Danish Future Study on Ageing to determine how future generations of older people would differ from current and previous generations and how the organisation

¹⁵ Leeson, G.W. (2006) One face of loneliness – old, homeless and forgotten, (in Danish), EGV/Kirkens Korshaer, Copenhagen; Leeson, G.W. (2011) Twelve days without a home – a diary with older homeless people (56 pp. in Danish), OSI, Copenhagen.

would need to adapt and develop to meet the needs and demands of these new generations. This was the first such future study in the world and it was a signal from the organisation that its work moving forward would be evidence-based. A director of research was appointed to oversee this research and to build up a broader research base for the organisation's many activities. The results from survey interviews with 40-64 year olds suggested – among other things – that the organisation would need to change dramatically, and the study has been repeated at regular intervals since 1985¹⁶. The result: DaneAge Association, and the story to the present day is one of continued success.

The original idea behind the Association was to develop a strong cross-generational membership association based in intergenerational solidarity that would campaign on behalf of older people, empower older people, and provide activities to engage older people. Membership is therefore open to anyone aged 18 years and over. The current membership subscription costs ca. £30 per annum.

The not-for-profit Association – which receives no direct government funding¹⁷ – was launched in early 1986 with a national distribution to every single household in the Country (more than 2 million at the time) of an eye-catching magazine explaining the need for such an organisation to empower older people and campaign for their rights to equal and dignified treatment in old age. The magazine – funded by EGV – included scientific evidence on ageing and stories from (ageing) celebrities.

Part of the attraction of this new kid on the block was the chance to get significant discounts on holidays with one of Denmark's leading tour operators (brokered through EGV's own travel bureau) for multigenerational holidays (with older family members).

¹⁶ Leeson, G.W. (2006) Attitudes to Ageing and Old Age – the Danish Longitudinal Future Study (73 pp.), DaneAge, Copenhagen.

¹⁷ The Association has received government funding for specific initiatives under government programmes.

The response was – even to those behind the launch – a massive success and within a short time the association was in the Guinness Book of Records as the fastest growing membership organisation. Membership went from a dozen or so (those behind the launch) to thousands and tens of thousands. Today, it stands at almost 1 million aged 18 years and over – that is out of a total of almost 5 million over 18 years of age.

The power of the association – both in financial and political terms – lies in its membership base. In those early years, the focus was on evidence-based campaigning and the Association built up a strong, well-regarded research and development department.

But the power and attraction of the organisation lies also in its volunteers.

Today, Bjarne Hastrup remains at the helm, and DaneAge is the second largest voluntary organisation in Denmark with 20,000 volunteers working locally, regionally and nationally in a variety of areas. Voluntary activities are all managed and coordinated by local elected committees, which are an integral part of the democratic structure and governance of the organisation (see below).

Locally, there are a variety of voluntary activities for members. These activities are mostly to support older people in the community, but they also address issues such as intergenerational relationships in the community. Many local committees have so-called *Generations Together* activities arranged in collaboration with local schools, kindergartens and school gardens. The commitment is no more than a few hours per month and tasks would include reading with the children, helping with homework (in after school classes), going for walks with the children, playing games and much more.

Since the late 1990s, the Danish Government has prioritised the roll out of new technologies to all age groups, including older people, and DaneAge has been involved in this ever since. Today, its local committee volunteers continue to offer

formal and more informal ways for older people to learn IT skills in educational settings but also in the home.

Befriending services are another of the offers from the organisation's local committees, covering everything from a regular morning telephone call and help in the home (not to clash with local authority home help services) to visits to care home residents.

Healthy Ageing has been a key message from DaneAge and many of its local activities and its local volunteers promote this, ranging from advice on diet to one-to-one training at home, from exercise classes to leisurely walks or hiking.

A final key element of local and national activities is campaigning to improve conditions for older people. As well as local authority seniors' councils, to which volunteers from DaneAge will seek election, the organisation has its own ranks of politically active volunteers at all levels.

For all volunteers, regardless of the type of volunteering, DaneAge provides training and support. Volunteers are coordinated in 10 regions and there are structures to enable the exchange of experience as volunteers.

The volunteers are a vital resource of the organisation, providing supportive services in local communities, but as mentioned another dimension of the power and attraction of the organisation is its membership. Its almost 1 million members aged 18 years and over are organised in 215 local committees, each of which has its own locally elected management and governing body. Members join the national organisation – to which they pay their membership fees twice a year – but then are assigned so to speak to their local committee area, where they can participate in the activities arranged by the local committee. Members have the opportunity to make use of a whole range of discounts on *experiences*, fitness, travel, spectacles, insurance, cultural events and restaurants across the whole country (mostly limited to older members). Almost 3000 such offers are available. The organisation also offers free telephone advice from professionals (lawyers, finance experts and social workers) relating for example to

housing support, social benefits, home help, wills, inheritance law. Members receive the DaneAge magazine six times per year along with an offers brochure and a local activities supplement (specific to the individual's local region). Members can also sign up to an email service which provides regular updates on new members-only offers, new relevant legislation, and healthy ageing advice/articles (keeping the brain active, diet and fitness).

The main governing body of the Association is the National Assembly of Delegates. Its members are the chairs of the local committees (elected by the local membership) and the nine members of the National Governing Body (elected for a 3-year term by the National Assembly of Delegates). The National Governing Body appoints the Directors, who are responsible for the Secretariat. Local Committee chairs and members of the National Governing Body all serve on a voluntary basis.

The Association also has 10 District Committees (which cover 10 regions of the country). These Committees appoint (on a voluntary basis) coordinators for policy, social humanitarian activities, IT, and activities. They are responsible also for courses in the district in addition to those provided nationally by the Secretariat.

Each Local Committee represents the views of the Association in respect of the local authority. Local Committees are supported financially by the National Association on the basis of size of the local area and the number of members in that local area.

Given the population size, the success of DaneAge in terms of its membership is noteworthy. But what is perhaps even more noteworthy is the fact that this organisation, campaigning to improve the well-being of older people in Denmark, has had such success in a country regarded by many as a model welfare state.

Discussion with the CEO, Bjarne Hastrup, shed some light on this phenomenon. It is important to recall the context in which the organisation was established, coming from the bedrock of a respected organisation, which had worked closely with local authorities for 75 years to provide specialised housing, residential care and day centre

facilities for older people across the country. In addition, the decision in 1986 to launch the Association was made on the basis of research evidence which suggested that older people of the future would be healthier, wealthier, more active and better educated – and wanted something which catered for their needs while they remained active (post-retirement in most cases). But the genius was the element of intergenerational solidarity. Denmark may well be a model welfare state, but people of all ages felt that things could be better for older people.

So, this was an organisation not of older people demanding more for themselves (the standard intergenerational conflict detonator) – this was an organisation of all generations holding decision-makers accountable and campaigning for a disadvantaged group who in Denmark, as elsewhere, were invisible and unheard.

The next stroke of genius was the impressive combination of national and local campaigning, harnessing the desire to contribute even after retirement (the army of volunteers), a wide range of locally organised attractive activities, and the focus of healthy, active ageing. And not to forget, while the organisation has a professional, highly skilled secretariat, they are intrinsically there for the members – and it is the members who showcase the organisation and campaign both locally and politically.

Not to mention the carrot of attractive discounts (yes, there are stair lifts and mobility scooters, but there are also hiking holidays, spa holidays and activities for you and your family members).

This is very much an organisation for those new older people, campaigning for their even older selves (and their parents and grandparents). And at £30, the membership fee will not break anyone's bank in Denmark.

This said, the numbers speak for themselves. And as Bjarne Hastrup himself states with a hint of surprise: *We are still growing.*

Another obvious case-study is the American Association of Retired Persons (AARP), of only because of its absolute size, although relatively speaking it compares with

DaneAge. It is also a far more controversial presence in the US than DaneAge has ever been in Denmark.

American Association of Retired Persons (AARP): this is an organisation in the United States which works on a whole variety of issues relating to citizens aged 50 years and over. Its membership numbers around 40 million persons. It is an interest-based, non-profit organization focused on enhancing the quality of life for those aged 50 years and over through advocacy, information, and service.

AARP was established in 1958 on the initiative of a retired Californian teacher, evolving from the National Retired Teachers' Association, also established by the same teacher in 1947. The idea behind AARP was to promote productive (active/healthy?) ageing, but also to promote health insurance for retired teachers, and was open to membership of anyone aged 50 years and over. A less flattering version of the organisations establishment is that it was established by the founder of an insurance group as a non-profit organisation working/lobbying on behalf of retirees with the ultimate aim of selling the group's insurance to these members. The truth of this version of history remains contested, but for whatever reason, AARP shifted the insurance available to members to a different provider.

Perhaps because of the links to and dependence on business, AARP was the subject of Senate investigation into its charitable status in the 1990s. This did not lead to a change of status, but the critics remained, claiming that AARP was *the biggest marketing operation in America and money-maker* and an organization whose practices were *the greatest abuse of American generosity I witnessed in my time in the U.S. Senate*¹⁸.

At the end of the 1990s, the organisation officially changed its name to AARP alone. This was apparently to reflect that it no longer only focused on people who had

¹⁸ US Senator Alan Simpson.

retired. At the same time, membership was opened to all ages (had they seen the success of the intergenerational solidarity dimension across the pond in Denmark?).

The attraction for younger people is clear. The question was: Should people in their twenties and thirties join AARP to take advantage of the benefits? These benefits did indeed seem attractive to all ages. Membership gave access to discounts on travel, dining, entertainment, and shopping, and much, much more. Compared with the membership fee (\$16 per annum at the time), the cost-benefit analysis was simple if a member took advantage of the available discounts¹⁹.

The organization is independent of all political or religious or other affiliation and it offers information services, volunteer opportunities, and events to its members, but *ideologically*, the most important aspect of AARP is that it lobbies powerfully on issues affecting older Americans at both the state and national governmental level. It has lobbied and campaigned on health care policy under numerous Presidents from both parties since the 1960s. However, there have been critics of the organisation's lobbying work²⁰.

Founded on insurance, this has been one of AARP's biggest successes, both in terms of numbers and income gained in the form of commission from companies using its name to sell their products. Also in this space, there has been criticism over the years, mainly in relation to value for money as far as the products are concerned, but also in respect of conflicts of interest when lobbying for reform that it would benefit from financially.

AARP has a number of affiliated organizations, for example:

AARP Research, a research group is committed to providing high quality independent research, trends, and insights on older adults and their families.

¹⁹ *Forbes*, August 31st 2017.

²⁰ *Los Angeles Times*, November 2003.

AARP Foundation, a non-profit charity helping people over age 50 who are at social and economic risk. Grants from the AARP Foundation aim to support sustainable solutions to the basic challenges facing low-income older adults, identifying evidence-based projects which can transform lives and communities and which can be replicated across the country.

AARP Services vets and then fosters relationships with companies offering products to AARP members. The main products are health care policies and long-term care products plus pharmacy services. Other products include life insurance, car and home insurance, technology services, a branded credit card and travel and leisure discounts.

AARP Insurance: Although AARP has its origins so to speak in the realm of insurance, AARP is not itself an insurance company. However, it does make available an impressive variety types of insurance to its members provided by vetted providers, over which AARP Services maintains quality control oversight. AARP offers several Medicare plans for members (and even non-members). Coverage is available to U.S. citizens or permanent residents aged 65 years and over, though there are exceptions for those under age 65 with a qualifying disability. AARP also offers a Dental Insurance Plan, and Vision Insurance, which offers regular comprehensive eye tests, discounts on frames and lenses, and loss-of-sight and diabetic-vision benefits.

AARP Short-Term Care Insurance covers assisted-living services but typically for no longer than 12 months including home healthcare, adult day-care, assisted living facility, nursing home care and hospice care. AARP Long-Term offers long-term care plans which help cover the costs of nursing homes, assisted-living facilities, and in-home care that are not covered by Medicare, Medicaid, or health insurance.

Other insurance offers (via independent, vetted providers) include life insurance, car insurance, golf cart and snowmobile insurance, boat and personal watercraft insurance, recreational vehicle insurance, home insurance, renters' insurance, mobile home insurance, motorcycle insurance and pet insurance.

As is the case with DaneAge, AARP is able to generate sufficient income from its membership and partnerships to guarantee it is in no way reliant on or linked to government funding for its day-to-day activities. Both organisations do, however, receive government funding for specific programmes.

A visit to the organisation's website reveals a multitude of services for members (members' benefits), ranging across work and jobs, health and wellness, brain health, retirement issues, insurance (covered above), finances, technology and wireless, travel, shopping and groceries, car services, family care-giving, restaurants, home and real estate, entertainment, community, advocacy, magazines and resources. Under each of these services, there is an impressive range of dedicated services. Locally, the organisation also offers volunteer opportunities.

What is interesting about the two case study organisations is the similarity of structure based on membership and volunteerism, while at the same time basing sustainability on a sound financial model revolving around extensive corporate partnerships. More interesting perhaps is the fact that these two organisations have emerged in two very distinct and different social frameworks.

The common theme perhaps is *new old age and older people*, something to which healthy ageing lends itself perfectly.