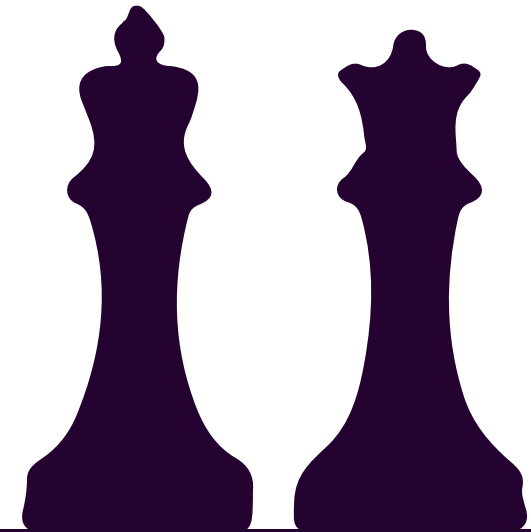


Dementia Services
Development Trust



**2017 ANNUAL REPORT FOR
DEMENTIA SERVICES DEVELOPMENT TRUST**



CONTENTS

Page 2 **Mission And Vision**

Page 3 **Re-framing Dementia**

- Uniformed Youth Groups
- Schools' Project

Page 4 • Faith groups

Page 5 • Arts Programme
• Outcome

Page 6 **Festival of Ideas**

Page 7 **Chennai Project**

Page 8 **Support for projects of the Dementia Services Development Centre at the University of Stirling**

- Creation of DSDC website

Page 9 • Publication of e-books
• Signage For Dementia

Page 10 **The New Old project**

Page 11 **Appreciation Of Frank Hitchman**

Page 12 **Abbreviated Financial Report**
• Donations

Dementia Services Development Trust

admin@dementiatrust.org.uk
www.dementiatrust.org.uk

VISION, MISSION, ACTIVITIES, AND PRINCIPLES

The Dementia Services Development Trust is the charity that was set up to fund the work of the Dementia Services Development Centre at the University of Stirling. It now continues to support that and other's work across the UK, and the rest of the world. Donations enable the Trust to fund additional projects, directly contributing to better standards of care for people with dementia. The Trust has become one of the leading charities of its kind in the world through support of projects co-funded by the Atlantic Philanthropies, the Big Lottery the Robertson Trust and a number of smaller trusts. Not least individual legacies, donations and gifts have been put to use to make things better for people with dementia.

VISION

To improve the lives of those living with dementia.

MISSION

To promote the best practice in the development of services of care and support of all those living with dementia and their carers.

ACTIVITIES

To provide grants and other financial awards, with the aim of:

- Supporting the provision of information, advice, support, education, training and other services relating to or ancillary to the needs of those living with dementia
- Promoting improvement in the care and support for those living with dementia by disseminating best practice and up to date information through knowledge transfer in Scotland and throughout the world: furthering the goals and objectives of the Trust, where appropriate, through funding specific work at the Dementia Centre in the University of Stirling
- Assisting and collaborating with other bodies and persons to improve best practice in relation to dementia
- Enhancing public knowledge and understanding of dementia

APPROACH

In pursuing its vision, the Trust will follow these principles:

- Proactive
- Pump priming
- Partnership



RE-FRAMING DEMENTIA

The Trust received a grant from The Atlantic Philanthropies to support work to transform the care of people with dementia in Ireland through reframing the perception of dementia. How people cope with dementia depends on how they perceive it, and media commentators and artists are hugely influential in shaping public perceptions. This project was aimed at disrupting unhelpful ways of thinking to create a sustainable culture for supporting people with dementia.

Following on from activity in Northern Ireland for around ten years Professor June Andrews and, the Dementia Services Development Centre of the University of Stirling, supported by The Atlantic Philanthropies through the Trust has gained a reputation there for authority and independence in thinking and delivery of innovation, based on research on health care improvement. The Centre operated a dementia centre in Belfast for more than six years. Links were also made with people working in dementia care in the Republic of Ireland, which were carried forward into this project.

The project, which had a number of components outlined below, aimed to create a sustainable change that, in the longer term, will result in a more positive framing of dementia in society, reduced stigma and better social wellbeing for those living with dementia. Successful outcomes were achieved over all.

UNIFORMED YOUTH GROUP

Having previously directly influenced the Brownies to introduce a badge relating to dementia the project encouraged the Scouts, working with Alzheimer's Society, to adopt dementia as one of the five areas of volunteering activity that form the focus for their suite of badges. In addition, and as a result, a public announcement was made that dementia as a topic is to be introduced to secondary schools in Northern Ireland.

SCHOOLS' PROJECT

A teacher at the school involved in the disruption project speaks of a transformation in the way the pupils think of older people and new ambition among them of pursuing careers in the care industry. She described how parents have learned about dementia through their children. From this, it seems clear that we have made a measurable change in the way this younger generation thinks about dementia and that their new thinking is influencing their families and community. The project highlighted that research shows that memory is not the main problem, or the most difficult for families to cope with. Further work would be needed to make sure that the educational work with young people does not continue to reinforce unhelpful stereotypical ways of thinking about dementia.



FAITH GROUPS

Following the report *Beset By Broken Promises* – a body of work undertaken in the first year of the programme involving faith leaders, people with dementia and their caregivers – the project held a large workshop in the Assembly Buildings conference centre in Belfast in March 2017. The objective of the event was to respond to the key questions about practical issues, such as what to do in the case of conflict between the roles and beliefs of individuals within families or between individuals and care workers. This was supported by the Presbyterian Church and the Catholic Church, and they drew in other partners.

With the support of the former Chief Nurse for Northern Ireland, project members met representatives from the health council of the Irish Catholic Bishops' Conference and academic staff teaching men for the priesthood at the National University of Ireland, Maynooth, to support their engagement with the question of how to help older people, parents and grandparents. It is encouraging that the Catholic Bishops' Conference of England and Wales supports this initiative and has expressed an interest in joining in. Materials for use in church communities have now been developed and have been used as stimulus material for workshops in Scotland and England as well as Northern Ireland. The materials are available for download on the Trust website and more than 1000 hard copies have been distributed.

The work was featured at a meeting of the Diocese of Down and Connor overseen by Bishop Noel Treanor and at the opening of the General Assembly of the Church of Scotland. Father Michael McGinnity of St Malachy's Church in Belfast and Mr Lyndsay Conway OBE, head of safeguarding for the Presbyterian Church in Northern Ireland, have been recorded describing the benefit of the materials and how they fit with their work going forward.

The church people involved regard this as a great success and have identified that they have specific needs going

forward that must be addressed. This includes better knowledge of how to communicate with a person with dementia, more clear information about safeguarding, and how to respond to the potential for abuse of older people.

The main issues are covered in the published guidance but there is recognition by DSDT of the need to build on this foundation. In addition, it is acknowledged that there exists a need to educate clergy on practical issues to make them more confident of inviting people with dementia into services.



ARTS PROGRAMME

Following two artists' residential programmes held in 2015 and 2016 across Ireland, several art projects, potential arts projects and longer-term development ideas have been supported as part of the Reframing Dementia programme. This has included discussions with the artists from both residential workshops, arts funding organisations across the UK, and potential funding partners for individual projects and for high-profile programmes, including one being commissioned by the BBC Northern Ireland. Some artists are actively pursuing projects jointly or individually.

We continue to support those who are working on dementia-related threads and want to work through what should happen going forward. By way of illustration, individual artists have already developed a range of different projects that engage with framing of dementia, including the following:

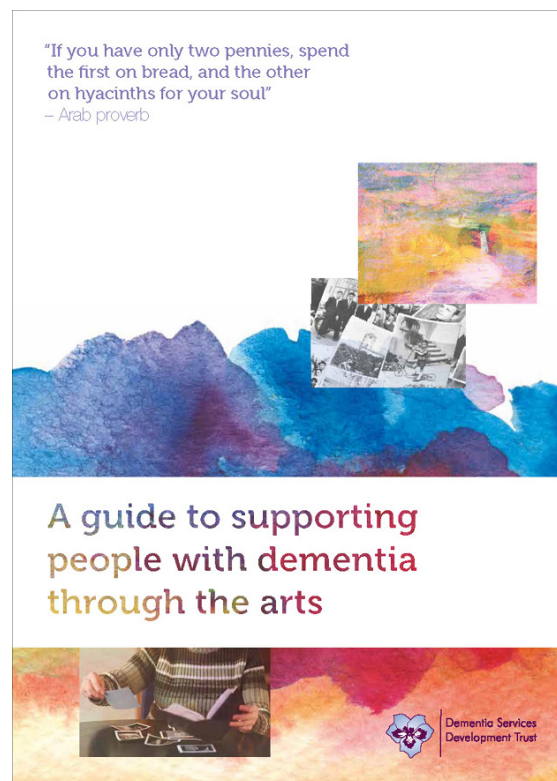
- Colin Gray has produced a suite of photographs of Derry that were featured on the DSDT website
- Linda McLaughlin has drafted a poem/play called Can You Hear Me? and taken her dementia play Descent to an international festival audience
- Stuart Davids and June Andrews delivered a pilot broadcast on BBC radio and are in discussion with an independent film company about a television series
- David Clegg's completion of his sound play on dementia
- Fiona Harrison has produced a draft composition called I'm An Old Woman Now

Discussion has continued with the BBC about approaches to the coverage of dementia in Northern Ireland and beyond, including scoping out a series of disruptive programmes for regional broadcast. These are at an early stage but the experience of engaging with commissioning bodies will form an important input into the work on framing of dementia which will be captured in blogs and in work going forward under a new project entitled The New Old.

More info: <https://thenewold.org>

A support pack has been produced for artists working in care homes and for care home staff considering using artists to work with people affected by dementia. Hard copies were delivered to key partners and the pack is also available for download. The pack is available for use anywhere and, having been released in Scotland, has featured on BBC Radio Scotland.

More info: dementiatrust.org.uk/programmes/supporting-people-with-dementia-through-the-arts/



OUTCOME

One of the aims of the Trust has always been to create a change in the way people think and act about dementia. We believe that there is a pressure to think in only one way and that people might fall back into that way of thinking without the influence of this programme. For some people, this project helped them to turn a corner and we hope they continue to think in different ways, by showing them that new ways of thinking are possible. With the churches, the children and the artists, we believe this has been radical and is sustainable. One artist said:

“It was amazing to think that dementia is not just about memory. That has radically changed the way I now look at dementia.”



FESTIVAL OF IDEAS

In 2015 and 2016, the Trust supported the Dementia Festival of Ideas, an exploration of new ways of thinking about dementia and a new agenda for the future led by Professor Andrews and the staff of the Dementia Services Development Centre and supported by Festival Director Mark Butler.

When the Trust helped set up the Centre at Stirling, dementia diagnosis was rare, education was almost non-existent and dementia was not a political priority. Now, it is centre-stage in the UK and most of the developed world, and there is a crowded field of people striving to improve the knowledge and education of health and social care workers, increase diagnosis, and make life better for people with dementia.

Through the Festival, a number of interesting findings arose. From the Big Ask survey, it became clear that men and women think about dementia in quite different ways. In the Ideas Labs, it became clear that there are many families and people affected by dementia who are not feeling any benefit from this new heightened interest in dementia and who are not receiving the services that are often described in strategies and policies. Through the political and economic masterclasses, it also became clear that the burden of care in developing countries still falls to women and, even in developed countries, that burden has a significant disproportionate effect on the economic and financial contribution that women make to their families and society.

As part of the Festival, held in Edinburgh, an arts and dementia masterclass gave rise to an important line of thought about the way culture is being regarded as therapeutic for people with dementia, even though there is no more evidence for this than for “dementia-friendly communities”, as uncovered by the literature search commissioned by the Trust as part of the Festival. Learning from this informed the work carried out across Ireland.

It is clear how unhelpful the current framing of dementia is for families. The media is telling people what to think about dementia, and the question is what motivates the media to take this line, and frame dementia in this way. Whatever the answer, there is an opportunity to help people to reframe the idea of dementia. This starts with helping people to understand that, in the absence of a cure, individual people and families need to be able to build their own resilience, financial, social and cultural, to deal with dementia, and may in fact have to support the health and social care system, rather than be supported by it.

The conversations that have taken place over the life of the Festival have at times been drowned out by government-funded public campaigns and PR, but a significant number of thoughtful people are starting to think in the same way, wondering how we will survive the future if the “cure in ten years” that was announced at the G7/8 Summit in December 2013 turns out to be a false hope. The outputs of the festival are recorded on the Trust website (dementiatrust.org.uk).

DEMENTIA
FESTIVAL OF
IDEAS



CHENNAI PROJECT

The Dementia Services Development Trust supported a programme in collaboration with the Schizophrenia Research Foundation (SCARF) to improve dementia services in Chennai, India. During a six-week placement in Scotland, a delegation from SCARF, based in Tayside NHS area, observed and learned from the services provided for people with dementia and their carers.

The visiting group was able to shadow psychiatrists, psychologists, and nurses and spend time with various teams such as the post-diagnostic service, community mental health teams, dementia liaison service (into care homes and community hospitals), specialist dementia wards and dementia day hospital. They were able to understand the systems and policies behind the services and also observe how care is practically provided. Based in Stracathro Hospital in Angus where most of the dementia professionals were based, the group attended conferences and masterclasses aimed at sharing information on dementia care and learned about services from various settings within Scotland and internationally.

The visiting group observed that dementia care services in Scotland are relatively highly-developed and that there exists more awareness and less stigma than in India, with this contributing to higher instances of early diagnosis and intervention. As a result, services in Scotland are more diverse at each stage of the illness, with guidance available via a well-thought-out legal framework that includes the National Dementia Strategy and Standards of Care for People with Dementia.

The main objective of this programme was for the SCARF group to use the knowledge gained through these observations to improve services in its organisation, which provides clinical and support services for people with dementia in Chennai, India. The Trust hopes to continue this partnership.



SUPPORT FOR DSDC PROJECTS AT UNIVERSITY OF STIRLING

CREATION OF DSDC WEBSITE

The Trust has supported the creation and running of a website for Dementia Services Development Centre (DSDC). The previous DSDC website had proved a little static and complex to maintain, as a result of which it was not serving its purpose.

The new website incorporates a number of features, including:

- Details of the work being done in Stirling, Belfast and elsewhere to support the creation of dementia-friendly communities, with strong features from the Stirling community

- Films and interviews on the outcomes of the creativity work in Northern Ireland
- A section on change in dementia, which acts as a brochure for the change and innovation consultancy provided by DSDC, including “deep dives”, change conventions and other high-impact practical support
- A section on housing that includes joint publications with national housing organisations and information on design for housing, including advertising for the housing courses offered by the centre
- A section on design that hosts the virtual dementia-friendly home and hospital, funded by other charities including the Nomine Trust and the Robert Bosch Foundation and based on research by the Thomas Pocklington Trust
- A section on education that provides a brochure on all the courses available through the DSDC
- A section on ideas that links to The Festival of Ideas, Masterclasses, Ideas Labs, The International Dementia conference and The Atlantic Philanthropies reframing work. Elsewhere on the website, there is a bookshop selling books, case studies of DSDC activity, details of staff, and a very active blog. More recently, modules have been added to offer online booking for training and events, online book purchase, an “innovation wall” and information requests, saving staff time

There is a section about the Trust itself with links to the donation sites. The website is illustrated with photography, mainly by Tony Marsh, with film footage by Pennie Taylor. Dr Tom Christie has provided many of the blogs. The Trust has provided the centre with an effective website that has contributed to its prosperity and reach.



**UNIVERSITY OF
STIRLING**



PUBLICATION OF E-BOOKS

Lighting is a popular topic within the DSDC's Design School and a publication on lighting is often used as a reference during the course. It is therefore a popular publication for Design School delegates to purchase.

Good lighting in buildings can help people to see what is around them, use landmarks to navigate, identify signs and spaces, see others' faces and participate in activities. Poor lighting can increase anxiety and may lead to trip and fall accidents if people cannot make sense of what is ahead of them.

Since the initial release of the existing offering (published in 2013), research on the impacts of light and lighting for health and wellbeing have advanced quickly. In particular, links between light and moods, appetite, depression, and incidence of falls are now much stronger. Lighting technology has, similarly, progressed rapidly, with several lightbulb types referenced in the existing book no longer available to purchase.

The new lighting publication is intended to be a complete overhaul, expansion, and technical upgrade of both written and illustrative content. While the previous publication was useful by being broadly informative on the basics of lighting design, it provided limited technical information for designers. Its contents are now regularly questioned by professional lighting engineers.

The updated book is within the DSDC design series, which is written for professionals rather than people with dementia and their carers. The new publication is anticipated to be accessible but also to become the global go-to technical handbook for professional lighting designers working in the dementia care, health and ageing sectors. It will also particularly be of interest to organisations and professionals involved in refurbishments and new building projects.

DSDC would like to ensure new publications reach e-readers, with digital editions of the lighting book complemented by a small print run to support marketing and sales activities.

SIGNAGE FOR DEMENTIA

Designers fail to realise the importance of good signage to the independence of people with dementia, often excluding signage altogether until it is raised as an issue by the DSDC design team. Existing buildings visited by the team commonly have very poor quality or ineffective signage schemes, a factor thought to be due to either lack of information or poor interpretation of the limited information currently available for signage for people with dementia.

The new book on signage published by DSDC proposes to be clear, informative, well-illustrated and accessible to all audiences. As signage can be one of the most effective

low-cost improvements to physical environments, it is anticipated that the book will be very popular among architects and designers for new environments and will allow quick and clear direction to be offered by the DSDC design team while delivering dementia design consultancy services. Most importantly, the publication of the signage book is expected to lead to environmental improvements that enhance the daily lives of people with dementia.

DSDC will ensure new publications reach e-readers, with digital editions of the signage book complemented by a small print run to support marketing and sales activities.

**LANGUAGE MENTAL HEALTH AGGRESSION
ANXIETY COGNITIVE BRAIN DEPRESSION ILLNESS
AGITATION
LOSS DEMENTIA ABILITY
SYNDROME DISORIENTATION TO LEARN
TREATMENT**

THE NEW OLD PROJECT

This is a web-based project to translate the learning from the Dementia Festival of Ideas and the Northern Ireland Reframing programme, funded by the Trust and by The Atlantic Philanthropies to create further impact and sustainability with increased reach especially in Scotland, and the rest of the UK.

The project generates, and makes available to the public, professionals and institutions, new thinking and reflections from a wide range of points of view, drawn from across the world. This will enhance public knowledge and understanding of dementia and also place this understanding in the broader context of older age – one of the key lessons of the Dementia Festival of Ideas and the Reframing programme in Northern Ireland.

It will influence and where necessary help change the future direction of dementia and related policy and practice in the area of older age by stimulating thinking and influencing what is actually done across traditional boundaries. This approach depends on increasing accessibility for people to a blend of the practical and the academic, the political and the professional, the campaigning and the factual. It will provide a space where people can explore questions about what needs to be done that is new, and what can be done, to improve the world of dementia affected by dementia and older age.

More specifically the project aims to improve the lives of older people by:

- Providing an evidence-based resource for the public, for professionals and for policy-makers to draw on in terms of information, advice, support and education
- Promoting new examples of thinking and best practice from leading experts across the world which go beyond dementia, as well as relating directly to dementia
- Developing new partnerships of thinking and practice which will support future innovation and change

The Festival of Ideas explored what would be needed to make further breakthroughs in the world of dementia. The NI Reframing programme has explored what works in terms of different approaches in thinking and practice. More recently, the Northern Ireland work has looked at whether “disruption” is important in making real change happen, asking if some thinking and practice needs to be challenged for new ideas and practice to be generated. This project is the next logical step – to build on the many ideas from the Festival and to explore in more depth the themes such of money, faith, the arts, and innovation, and their role in the future of the lives of people affected by dementia and frailty.

More info: <https://thenewold.org>

THE NEW OLD



APPRECIATION OF FRANK HITCHMAN

BY EMERITUS PROFESSOR JUNE ANDREWS

Frank Hitchman was, until his death, the secretary of the Dementia Services Development Trust. The Dementia Services Development Centre (DSDC) at the University of Stirling is the brainchild of the Trust.

Through his efforts, Frank led to transformation in the lives of many thousands of people with dementia and their carers. Other dementia centres across the UK have attempted to replicate the model of the Centre without success, and the difference between them and the DSDC is Frank Hitchman and the Trust he sustained for well over a decade. Now, the Centre that he helped to create is recognised across the world and is in demand internationally as a leader in the field of dementia and Alzheimer's. None of this would have been possible without the sustained commitment of Frank Hitchman.

Frank did a number of things personally. He led a group of people who raised around £3million to create the Dementia Services Development Centre's headquarters at Iris Murdoch Building, which was the first dementia-friendly public building in the world when it was opened in 2003. The DSDC is now acknowledged as an international source of evidence-based expertise and support for people who are struggling to live with, or support people who are living with, dementia.

Frank's vision was for something different from the lobbying role of advocacy groups like Alzheimer's Scotland or the Alzheimer's Society, and complementary to their work. The DSDC was to focus on what is practical and makes a difference, and to deliver this at low cost or free to people who could not afford it. His dogged determination to make this work, and his wise counsel for the staff of the Centre and the trustees of the Trust over many years have had a huge impact.



In his personal contribution to fundraising since the centre was opened, Frank created an amazing range of cultural events that brought money into the Trust. Examples include an art exhibition, where a donated percentage of sales raised tens of thousands of pounds for the Trust. When sales became slow, he himself bought pictures. He arranged for a harpsichord concert in the Signet Library in Edinburgh. Some might have thought that the time and effort of this might produce small receipts but he calculated wisely that the sort of people who attended were in a great position to make large donations.

He has used all his contacts in the arts world to put on premium events that brought friends to support the work of the Centre. His energy and capacity to get others to open their chequebook is legendary. He persuaded the Countess of Wemyss to open her home, convinced Dame Judi Dench to formally open the Iris Murdoch Building and sold her the idea of becoming a patroness of the Trust, a role in which she continues fourteen years on, bringing much-needed publicity that also attracts resources.

He had a great financial career but amusingly described himself as a "double entry bookkeeper". In that role, he presided over the finances of the Dementia Services Development Trust committee for the ten years I was there and for some time before that. In this voluntary role, he wrestled with minor complications of small amounts of cash that made a huge

difference to a lot of people, in exchange for a cup of black coffee and a biscuit. After a career at the top, as the finance director of a global oil company, that was impressive. He spent hours with paperwork and with auditors, and carefully watched over all the resources.

Frank diffidently accepted an honorary degree from the University of Stirling in recognition of the fact that many millions have been donated through the Trust to the work of the DSDC. He allowed the University to name the gallery in the Iris Murdoch Building "the Frank Hitchman Gallery" but the brass plate had to be modest in size, and near the coat racks. I can think of no-one who has done more than Frank.



INCOME AND EXPENDITURE

Year Ending 31st March	2017 £	2016 £
INCOME		
Voluntary Income:		
Donations	33,103	13,501
Legacies	0	12,000
Charitable Trust	52,000	239,100
Grants	3,992	112,666
Investment Income	<u>781</u>	<u>2,266</u>
	89,876	379,533
EXPENDITURE	(-204,472)	(-339,323)
Net Incoming/ (Outgoing) Resources	(114,596)	40,210

Grants agreed during the calendar year 2017:

Chennai Project	£10,000
Dementia Centre, University of Stirling	£32,000
'New and Old' website	£30,000
Raindog films: 10 Myths about Dementia	£10,000

Full accounts can be found at www.dementiatrust.co.uk

DONATIONS

All donations, whatever their size, will help us to:

- Transform how people with dementia experience life in every part of the community because people understand better the needs of people with dementia
- Provide education for a wide range of organisations, such as the police service, who are often called when someone is lost
- Set a standard for the design of care homes and hospitals, educating architects to help them create buildings that will help a person with dementia remain independent for as long as possible
- Produce easy to read guidance for busy health and social care professionals who are on the front line of diagnosing and supporting people with dementia
- Provide direct training and support for families

How to support us

As a charity, we rely on donations to achieve our goals of improving the quality of life for people with dementia, their carers and families. There are many ways you can help us make a difference, including making a monthly donation or leaving us a gift in your will. Please contact us to find out more.

www.justgiving.com/dementiaservices
www.dementiatrust.org.uk



Dementia Services Development Trust
c/o Morton Fraser, Quatermile Two
2 Lister Square, Edinburgh EH3 9GL
Charity Registration No: SCO 16905

Dementia Services Development Trust

admin@dementiatrust.org.uk
www.dementiatrust.org.uk