Scotland’s Third National Dementia Strategy

Response to the Dementia Dialogue 2015/16

Life Changes Trust
March 2016
The Life Changes Trust was established by the Big Lottery Fund with a National Lottery grant of £50 million to drive transformational improvements in the quality of life, well-being, empowerment and inclusion of people affected by dementia and young people with experience of being in care.
Introduction

The Life Changes Trust welcomes the opportunity to participate in the Scottish Government’s Dementia Dialogue. We are an independent Trust established in 2013 by the Big Lottery Fund Scotland to drive real and meaningful improvement in the lives of young people with experience of being in care and people affected by dementia (both people living with dementia and carers). Between 2013 and 2023, the Trust will strategically invest £25 million to improve lives of people affected with dementia.

To date, the Trust has committed £8 million of funding to a variety of projects that will help contribute to the following outcomes for people affected by dementia:

- I live in a place that suits me and my needs
- I am able to be as independent as possible
- I get the help I need when I need it
- I feel safe, listened to, valued and respected
- I am empowered to do the things that are important to me

The Trust will continue to invest between now and 2023 in projects, the influencing of policy and the embedding of sustainable practice across Scotland.

If there are any questions about this response, please contact Anna Buchanan, People Affected by Dementia Programme Director at:

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Summary

- The Life Changes Trust proposes that the first Commitment of the Third National Dementia Strategy is a commitment from the Scottish Government to listen actively to people living with dementia and carers from across Scotland.

- The Life Changes Trust asks that in the Third National Dementia Strategy the Scottish Government retains its commitment to providing safe and supportive home environments and notes the work being carried out by the Trust that will help support this commitment.

- The Life Changes Trust believes that since transport and signage are such important areas of concern for people living with dementia, these should be acknowledged in the Third National Dementia Strategy. The Strategy also needs to be clear that its effective delivery will require cross-portfolio working. The Minister for Transport and Islands should work to ensure that the aspects of transport devolved to Scotland, or within Scotland’s sphere of influence, become more dementia friendly between 2016 and 2019.

- The Life Changes Trust would like to see the Third National Dementia Strategy recognise more explicitly the importance of self-directed support for people with dementia, particularly in the self-management stages of the condition. There should be a commitment to developing deeper understanding of the relationship between self-directed support and the ‘8 Pillars’ model.

- In principle, the Life Changes Trust supports the relocation of post-diagnostic services to primary care but seeks assurances that primary care services across Scotland are willing and equipped to accept this role.

- The Trust supports a human-rights-based approach to palliative and end of life care for people with dementia. We believe that all specialist and generalist staff involved in palliative and end of life care should be trained in how to care for someone who has dementia and is nearing the end of their life. This includes junior staff who often administer care and support families in the latter stages of a person’s life.
The Life Changes Trust is firmly of the view that the Third National Dementia Strategy should promote the development of community-led dementia friendly communities.

The Scottish Government should ensure that, as the Third National Dementia Strategy is implemented, there is:

- more transparent and regular reporting than has been the case to date;
- reporting in ways that are acceptable and accessible to people living with dementia;
- a separate, independently chaired monitoring group that includes strong representation from people living with dementia and carers.

There should also be stronger reporting requirements for Integrated Joint Boards at the local level so that data can be aggregated and a clear national picture can be painted of how the Third National Dementia Strategy is being realised across Scotland.

Reflections on the National Dementia Strategy 2013-16

When considering the next iteration of the National Dementia Strategy, it is worth reflecting on what has been achieved by the previous one. The fact that Scotland has had a National Dementia Strategy since 2010 demonstrates the clear commitment of the Scottish Government to ‘getting it right’ for people living with dementia and their carers. In many respects Scotland is a leader in dementia and the Scottish Government is to be congratulated on its determination and ambition.

There were 17 commitments made in the 2013-16 Strategy which were each aimed at achieving positive outcomes for people living with dementia. It is difficult to tell at a glance what progress has been made against each of these commitments, particularly since the Monitoring and Implementation Group set up to report on progress has not published annual reports in June 2014 and June 2015 as was expected. The Life Changes Trust would encourage the Scottish Government to explore ways of clearly reporting on progress, particularly in a way that is accessible to people living with dementia (see below, ‘Accountability’).
Commitment 1 of the 2013-16 Strategy states, “We will sustain and, where appropriate improve further, dementia diagnosis rates”\(^1\). It is not clear whether **dementia diagnosis rates** have increased over the past three years, but feedback to the Trust from the various projects it funds indicates that they have not. There are many people attending Trust-funded projects who show all the signs and symptoms of dementia but who do not have a formal diagnosis or are struggling to get one. The knock-on impact of this is that they and their carer(s) are unable to access post-diagnostic support and, often, other forms of support.

The Trust has become aware, through one of the dementia friendly communities it funds, that people who are deaf are finding it exceptionally difficult to receive a diagnosis of dementia. One reason for this is because there is a lack of knowledge amongst professionals in how to diagnose dementia when a person is deaf. This deserves special consideration.

The picture painted anecdotally of **post-diagnostic support** is that it is ‘patchy’ and that Link Workers are often carrying unmanageable caseloads. However, where post-diagnostic support is working well it is bringing enormous benefit to families living with dementia. It is enabling them to connect to the support their community has to offer and is giving clear and helpful information. We will know more about the official figures on the national post-diagnostic HEAT Standard when they are published later in 2016. It would, however, have been helpful to have known these figures earlier, and certainly during the Dementia Dialogue discussions on the proposed Third National Dementia Strategy.

The five **‘8 Pillar’ test sites** which focus on integrated, intensive, home-based, co-ordinated care for people with mid-stage dementia (and support for families) have yet to be formally evaluated. The evaluation report will be available later in 2016. Again, it would have been useful to have this report to help inform the Third National Dementia Strategy. There are three helpful case studies on the Focus on Dementia website which point to some of the outcomes being achieved by the sites in East Sutherland, Glasgow and North Lanarkshire.\(^2\) It is hoped that the external evaluation being carried out will demonstrate clear outcomes for people living with dementia and their families and explain how these outcomes are being achieved.

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2. [http://www.qihub.scot.nhs.uk/media/857011/case%20studies%20from%20some%20of%20the%208%20pillar%20test.pdf](http://www.qihub.scot.nhs.uk/media/857011/case%20studies%20from%20some%20of%20the%208%20pillar%20test.pdf)
The impact of Nurse Consultants and Dementia Champions was evaluated in their early stages. The evaluation report observes that “both roles have been successful in raising the profile of dementia at a local level, both strategically and operationally, and to some extent nationally”. In terms of outcomes for people living with dementia, the report states, “while it is too soon in terms of systematically evidencing improvements in the care of people with dementia, we can infer that (Nurse Consultants’ and Dementia Champions’) activities will support improved outcomes and experiences”. The Scottish Government and NHS Boards are building on the initially positive steps made, particularly through the Focus on Dementia improvement programme, and we look forward to learning more in due course about the ongoing impact of nurse consultants and dementia champions.

The National Dementia Strategy 2013-16 Commitment 5 states, “We will take further action to support safe and supportive home environments and the importance of the use of adaptations and assistive technology, in maintaining the independence and quality of life of people with dementia and their carers”. Alzheimer Scotland has produced the extremely useful Technology Charter for People Living with Dementia in Scotland which highlights the benefits of accessing technology and, most importantly, emphasises that “technology augments - but does not replace - human intervention”. This message, that technology should enhance human relationships rather than replace them, is one that has come through strongly from people affected by dementia in the Trust’s own work.

The Life Changes Trust has recently announced a three-year £1 million pilot project in partnership with Care and Repair which will evaluate the benefits of early action in the home in order to help people living with dementia remain at home for longer (see below, ‘The Third National Dementia Strategy’).

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3 [http://www.nes.scot.nhs.uk/media/2711493/impact_evaluation_-_final_report.pdf](http://www.nes.scot.nhs.uk/media/2711493/impact_evaluation_-_final_report.pdf)
7 [http://goo.gl/ynUUr3](http://goo.gl/ynUUr3)
8 [http://goo.gl/ynUUr3](http://goo.gl/ynUUr3), p.4
It seems to us that whilst progress has been made by virtue of the Commitments set out in the 2013-16 Strategy, it is impossible to tell exactly how much progress has been made and what still needs to be done to improve outcomes for people living with dementia and carers. This is primarily due to the fact that much of the information that is needed to make that judgement has not yet been published, e.g. the ‘8 Pillars’ test site evaluation, benchmarking framework data and post-diagnostic HEAT Standards data. Therefore, in the Third National Dementia Strategy the Life Changes Trust would like to see clearer communication of data and outcomes on an ongoing basis.

The Third National Dementia Strategy

Scotland’s Third National Dementia Strategy provides an opportunity to build on, and learn from, the work of the first two Strategies. We would, therefore, hope to see the Third Strategy shaped by the findings of the ‘8 Pillars’ test site evaluation – even if this means delaying the publication of the Third Strategy so that this learning can be incorporated.

Scotland’s National Dementia Strategy is to be implemented and reported on at a local level as well as a national level. Clearly, the new Integrated Joint Boards that have been established for joint working in local areas across Scotland will have a critical role to play in adopting and funding good practice that benefits people living with dementia and carers. The Integrated Joint Boards will want to make plans based on the strongest evaluation evidence possible as they develop their local strategies for implementing the National Strategy and tailor their work to their particular community needs. The ‘8 Pillars’ evaluation findings will be important in doing this - as will evaluation findings from work carried out by other organisations, such as the Life Changes Trust, Joseph Rowntree Foundation and Age Scotland.

Listening to people living with dementia and carers

People living with dementia are very clear that they believe in ‘nothing about us without us’. Scotland has led the way in establishing the Scottish Dementia Working Group and several countries are following that example. Scotland also has the National Dementia Carers Action Network which is a national campaigning and awareness raising group whose members all have experience of caring for someone with dementia.

It is important that people with dementia and carers have a voice at a local level and are supported to do so. Many organisations wish to have a ‘person with dementia’ or a ‘carer’ on their Board or advisory group yet do nothing to enable them to attend, for example, by covering travel and caring costs. Often papers are sent out too late for the person to have an opportunity to read and digest them. And on many Boards and Committees, the person with dementia or carer does not have a vote.

The Life Changes Trust, in partnership with the Joseph Rowntree Foundation and Comic Relief, is funding the development of the Dementia Engagement and Empowerment Project (DEEP) network across Scotland. A new national co-ordinator will shortly be appointed. DEEP is a network that supports independent groups of people living with dementia to try to change services and policies that affect their lives. See http://dementiavoices.org.uk/

Through the Third National Dementia Strategy, the Scottish Government could be clear in its expectations that organisations and agencies providing services for people affected by dementia engage in active dialogue with them so that they can contribute to the shaping of services that will meet their needs and expectations.

The Life Changes Trust proposes that the first Commitment of the Third National Dementia Strategy is a commitment from the Scottish Government to actively listen to people living with dementia and carers from across Scotland.

Housing, equipment and adaptations

Housing partners have a significant contribution to make to the success of integrated joint working yet are frequently overlooked. The commitment made in the 2013-16 Strategy to “taking further action to support safe and supportive home environments and the importance of the use of adaptations...in maintaining the independence and quality of life of people with dementia and their carers” (Commitment 5) should be continued in the Third Strategy.

The policy priority of keeping people in their own homes for longer will fail if intervention in the home is not provided at an early enough stage. It is for this reason that the Life Changes Trust is funding a three-year pilot project in partnership with Care and Repair, which will evaluate the extent to which early action in the home enables a person to live there for longer and reduces reliance on expensive services. The pilot will operate in Aberdeen, Angus and Lochaber/Skye/Lochalsh.
The Trust is also funding work that will draw together learning from across Scotland on best practice in housing (public and private) for people living with dementia – including rural housing. This will culminate in a Housing and Dementia Summit which will include partners from a wide range of agencies and locations and will lead to further work.

**The Life Changes Trust asks that in the Third National Dementia Strategy the Scottish Government retains its commitment to providing safe and supportive home environments and notes the work being carried out by the Trust that will help support this commitment.**

**Transport and signage**

Two areas of concern for many people living with dementia have been absent from both National Dementia Strategies to date: transport and signage. Dementia friendly transport is essential to help many people with dementia and carers maintain their independence and confidence. The Scottish Dementia Working Group have recently launched a video\(^\text{10}\) on Travelling with Dementia and the Life Changes Trust is funding work that will enable people living with dementia and carers to engage with the travel industry and talk with them about what needs to change so they can use transport and transport systems confidently.

There is a clear link between lack of good transport and isolation and loneliness. This was a key finding of the Age and Social Isolation Report from the Equal Opportunities Committee\(^\text{11}\) which recommended that the Scottish Government works with local authorities to improve the availability of community and public transport.

People with dementia have talked about confusing signage and symbols which can lead to them becoming lost, confused or embarrassed. The Life Changes Trust is funding scoping work to find ways in which to make the existing British Standards Institute symbol sets more dementia friendly, as well as identifying any gaps in the symbol set. More generally, dementia friendly communities across Scotland are working with local shops and businesses to help them understand how to use signage effectively so that people with dementia can access their services more easily.

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\(^{10}\) [https://www.youtube.com/watch?v=l3UfTXaNfw0](https://www.youtube.com/watch?v=l3UfTXaNfw0)

The Life Changes Trust believes that since transport and signage are such important areas of concern for people living with dementia, these should be acknowledged in the Third National Dementia Strategy. The Strategy also needs to be clear that its effective delivery will require cross-portfolio working. The Minister for Transport and Islands should work to ensure that the aspects of transport devolved to Scotland, or within Scotland’s sphere of influence, become more dementia friendly between 2016 and 2019.

Self-directed support

Scotland’s National Dementia Strategy sits within a wider context and one key component of post-diagnostic support and self-management of dementia can be good access to self-directed support. We know that work carried out by organisations like Alzheimer Scotland has shown that self-directed support offers real benefits to people with dementia. The Life Changes Trust ran a short pilot scheme in 2014 which offered sums of up to £500 to individuals living with dementia and carers so they could choose to do or purchase something that would make a real difference to their life and sense of wellbeing. The evaluation of the pilot showed that a relatively small sum of money, spent as the individual chose, could have immediate impact on wellbeing but also longer term impact and benefit. The Trust will carry out the scheme one more time in five areas throughout Scotland in 2016/17 and, at the same time, carry out further policy work on self-directed support, exploring the reasons why many people with dementia cannot access it and how these barriers can be overcome.

The Life Changes Trust would like to see the Third National Dementia Strategy recognise more explicitly the importance of self-directed support for people with dementia, particularly in the self-management stages of the condition. There should also be a commitment to developing deeper understanding of the relationship between self-directed support and the ‘8 Pillars’ model.
Relocating post-diagnostic services into primary care

The Life Changes Trust recognises the potential benefits of relocating post-diagnostic services to primary care settings and hopes that this would make getting a diagnosis and accessing post-diagnostic support easier. It is not clear how much engagement the Scottish Government has had with GPs and other primary care providers on this suggested redesign. One key benefit of the suggested approach would be the increased possibility of providing care and support at a very local level, with the opportunity for people living with dementia and carers to be quickly referred to known and trusted local dementia initiatives, peer support groups and information and advice services (if the primary care providers know about them).

In principle, the Life Changes Trust supports the relocation of post-diagnostic services to primary care but seeks assurances that primary care services across Scotland are willing and equipped to accept this role.

Palliative and end of life care

The Life Changes Trust agrees wholeheartedly with the Scottish Government that palliative and end of life care for people with dementia should be a policy priority. There should be specific focus on anticipatory care planning and the rights of the person with dementia and the carer, particularly Article 3 rights (not to be subjected to inhuman or degrading treatment) and Article 8 rights (right to private and family life), with Article 14 (the right not to be discriminated against when securing these rights).  

It is important to recognise that people with dementia are more likely to die with dementia than of dementia - although dementia is a life-shortening illness, another condition or illness may actually cause a person’s death. Therefore, it is important that this is recognised and everyone who works in the field of palliative care is made aware of the specific needs of a person with dementia (which will, of course, vary depending on the type and extent of dementia a person has). There is an enormous amount of valuable learning to be gained from existing palliative care practice and there is a strong argument to be made for the ‘mainstreaming’ of dementia awareness and training in all palliative and end of life care services.

13 European Convention on Human Rights
The Trust is aware that the Scottish Government wishes to test and evaluate Alzheimer Scotland’s Advanced Dementia Practice Model. We would be keen to see the Model evaluated from ‘Day 1’ of its implementation and evaluation findings published on a regular basis so that any issues can be addressed at the first opportunity and good practice rolled out at the earliest point possible (‘knowledge into action’ approach). It is also important to note that a person may die with mild or moderate, rather than advanced, dementia and so the focus should not be on advanced dementia only.

**The Trust supports a human-rights-based approach to palliative and end of life care for people with dementia. We believe that all specialist and generalist staff involved in palliative and end of life care should be trained in how to care for someone who has dementia and is nearing the end of their life. This includes junior staff who often administer care and support families in the latter stages of a person’s life.**

**Community-led dementia friendly communities**

For almost a year, the Life Changes Trust has funded and helped develop fourteen dementia friendly communities across Scotland. Four of these are geographical communities, six are local communities of interest and four are national communities of interest – all of which engage with their local communities through the work they do.

In taking a grassroots-led approach, the Trust has deliberately moved away from a purely ‘top-down’ statutory-sector-led approach to dementia friendly communities and taken as the starting point the places which people with dementia and carers themselves identify as their ‘community’. In the next year or so, the Trust hopes to provide funding to more communities across Scotland that are seeking to become dementia friendly.

On 21 September 2016, the Trust will host a conference entitled ‘Community and Dementia’ which will provide each of the fourteen existing communities with an opportunity to talk about the work they are doing and the outcomes they are achieving for people with dementia and carers.

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14 [http://www.alzscot.org/campaigning/advanced_dementia_model](http://www.alzscot.org/campaigning/advanced_dementia_model)
The communities funded by the Trust produce evaluation evidence on a six-monthly basis and the Trust will regularly publish summaries of the evidence and findings so that others can learn from it too. The Trust brings all the projects it funds together every three months so that learning can be shared quickly and knowledge put into action. This also provides opportunities for networking and the development of new partnerships. The majority of these gatherings are open to anyone who wants to come along.

The outcomes to which each of the communities works are taken from the perspective of the person with dementia or carer:

- I have a significant say in how my dementia friendly community is run.
- I know I have a community of support around me.
- I am included.
- I feel safe, listened to, valued and respected.
- I am empowered to do the things that matter to me.

Dementia friendly communities also assess their output activities, such as how they are raising awareness of dementia, how they are developing new ways of working in partnership, and how they are helping to build community capacity.

In the coming year we will be looking more closely at dementia friendly communities in the context of community development. This is where we believe the key to success lies. We do not believe that a purely ‘top-down’ approach will meet the needs of people living with dementia and carers in a way that is meaningful or involve them in a significant way. A dementia friendly community should be neither a tick-box exercise nor tokenistic in the extent to which it involves people with dementia and carers - they must be at the heart of the community and its development, and supported to do so.

The Life Changes Trust is firmly of the view that the Third National Dementia Strategy should promote the development of community-led dementia friendly communities.
**Reporting and accountability**

The **Dementia Strategy Implementation and Monitoring Group** is responsible for reporting on the progress of the National Dementia Strategy:

“We will put in place robust arrangements to ensure delivery of our agreed commitments and to enable us to track and monitor improvement in outcomes over time through the establishment of a Dementia Strategy Implementation and Monitoring Group which will report annually on progress and review the Strategy by June 2013.”

“The Implementation and Monitoring Group will be chaired by the Scottish Government and include representatives of key stakeholders, including those from the statutory, voluntary and private sectors, the new scrutiny bodies, as well as people who have dementia and their carers.”

*(Dementia Strategy 2010-2013, pp 54&55)*

“As in the first Dementia Strategy, there is a shared commitment to take forward transformational change, with the commitments designed to help deliver change across a range of service areas and organisations with different governance and accountability arrangements. We will continue over from the first Strategy an Implementation and Monitoring Group, chaired by the Scottish Government and including representatives of key stakeholders from the statutory, voluntary and private sectors, the scrutiny bodies, as well as people who have dementia and their families and carers.”

*(Dementia Strategy 2013-2016, pp 22&23)*

The Monitoring and Implementation Group is responsible for ensuring delivery of the Strategy’s Commitments and any further work that should be carried out to meet those commitments. It should also monitor and track change and improvement over time in respect of dementia services. The Group is to prepare Annual Reports on progress and commission revisions to the Dementia Strategy, which take account of progress and learning. The Group should also routinely publish progress minutes, papers and reports on the Scottish Government website.
Public-facing annual reports from the Monitoring and Implementation Group were published in June 2011 and June 2012, but there have been no further annual reports. There is limited information on the Scottish Government website and the commitment to publish minutes, papers and reports has not been met.

For the Third National Dementia Strategy, the Life Changes Trust would like to see far clearer, dementia friendly reporting on progress against the Strategy and more transparency on the role and business of the Monitoring and Implementation Group. We would also respectfully suggest that the Monitoring and Implementing Group should be two groups: one that tracks and reviews implementation of the Strategy, and another independent group that monitors progress against the Strategy commitments and outcomes from a non-governmental perspective.

The current Monitoring and Implementation Group members come, in the main, from the government, the wider statutory sector and Alzheimer Scotland. We suggest that the second independent group mentioned above acts as a critical friend in assessing progress and outcomes, and is chaired by someone who is independent of the government. The membership of this group should include strong representation from people living with dementia, current carers, former carers and others who are active in the dementia field. People living with dementia and carers will require financial and practical support to attend meetings and meetings should be convened to suit their needs rather than primarily those of any professionals involved.

Any progress or annual reports published by the Scottish Government should be readily accessible to people living with dementia and carers and there should be greater consideration of how this could be achieved, for example, the use of video as well as written material. It would be helpful if the Government could consult with people living with dementia and carers to find out how they would like to receive progress reports.

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16 [http://www.gov.scot/Topics/Health/Services/Mental-Health/Dementia](http://www.gov.scot/Topics/Health/Services/Mental-Health/Dementia)
At a local level, it would be helpful to have more clarity in the Third National Dementia Strategy on how Integrated Joint Boards should report on outcomes achieved and progress made through their local action plans.

The Scottish Government should ensure that as the Third National Dementia Strategy is implemented there is:

- more transparent and regular reporting than has been the case to date;
- reporting in ways that are acceptable and accessible to people living with dementia;
- a separate, independently chaired group that includes strong representation from people living with dementia and carers.

There should also be stronger reporting requirements for Integrated Joint Boards at the local level so that data can be aggregated and a clear national picture can be painted of how the Third National Dementia Strategy is being realised across Scotland.

**Conclusion**

The Life Changes Trust looks forward to seeing the proposed Third National Dementia Strategy. The work that the Trust funds is aimed at achieving transformational and sustainable change in the lives of people affected by dementia in Scotland. It is our hope that much of what we do will serve to support and complement the Third Strategy so that by 2019 people with dementia and carers are able to say that the efforts of many organisations in Scotland are making a real positive difference to their lives.
Getting in touch

If you have any queries or wish to share your views and ideas, you can contact us in a number of ways:

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