

Alzheimer Scotland

ILC-UK – Commission on Dementia and Music

Introduction

Alzheimer Scotland is Scotland's leading dementia voluntary organisation. We work to improve the lives of everyone affected by dementia through our campaigning work nationally and locally, including facilitating the involvement of people living with dementia in getting their views and experiences heard. We provide specialist and personalised services to people living with dementia, their families and carers in over 60 locations and offer information and support through our 24 hour freephone Dementia Helpline, our website (www.alzscot.org) and our wide range of publications.

Alzheimer Scotland welcomes the opportunity to contribute to this call for evidence.

Definition

Alzheimer Scotland believes that there needs to be a clear distinction between social supports and using of music in service settings as part of a range of therapeutic interventions, and music therapy as a highly specialised psychological clinical intervention, delivered by Health and Care Professions Council (HCPC) registered Music Therapists.

Both are important in supporting the wellbeing of the person with dementia, their families and carers. The use of music in different ways and its impact will vary from person to person, with the appropriateness of musical interventions being unique to each individual. However, the specialist skills and knowledge of a HCPC-registered Music Therapist require distinct knowledge, skills and understanding to identify specific outcomes for the person with whom they are working, considering the specific contribution Music Therapy can play as part of holistic, integrated care and support. Part of this includes offering assessments and identifying other interventions or treatments which may benefit the person.

Alzheimer Scotland recognises that Music Therapy and musical interventions have an important role to play as part of a therapeutic intervention offer for people with dementia, their families and carers. However, it is one of many therapeutic interventions that can support this and must be considered alongside other interventions including Art Therapy, Occupational Therapy and Cognitive Stimulation Therapy.

Delivery and Benefits of Music

In community settings across Scotland, it is Alzheimer Scotland's understanding that the majority of initiatives around music and dementia are delivered by the third sector and funded through fundraised income or grant applications to charitable funds. Our own resource centres and services provide specialist therapeutic interventions which support people with dementia to maintain their skills and take part in meaningful activities such as musical reminiscence, singing and other music-based interventions; these provide stimulation and social interaction which

improve the person's wellbeing and reduce isolation. In addition, there are a number of music-based interventions which are used in both acute care and residential care settings.

As part of the Practitioner Research Project (PRoP) run by the Institute for Research and Innovation in Social Services (IRISS), an Alzheimer Scotland member of staff demonstrated the use of music in people's own homes, even where not used formally as a 'therapeutic intervention', [could help improve mood and relax a person with dementia, allowing carers a brief period of rest](#). Similarly, our experience of working with organisations which delivered home-based musical supports was, anecdotally, very popular with both people with dementia and their carers.

Across Scotland, Alzheimer Scotland supports a number of musical based services and supports providing people living with dementia, their friends and carers the opportunity to take part in a stimulating, meaningful and enjoyable activities, which reduce isolation and provide opportunities for verbal and non-verbal communication. In these groups, people's verbal communication is often brought out; some individuals who previously spoke seldom will, for a short time, begin to speak about the music and experiences attached to the music. These groups run in different ways, with some primarily focused on singing such as the Forget-Me-Notes choir in Edinburgh, which has been involved in a number of projects in Scotland and has attracted interest from some housing associations which support people with dementia. Additionally, we have Music Memories groups in Aberdeenshire which have included attendees from local care homes and cross-generational links being established with the community through involving pupils from local schools who play instruments and sing for the groups. Another example is the Every Voice Choir in West Dunbartonshire which involves people at different stages of the condition and has performed at different events in the locality, including in the local acute hospital.

These groups work in such a way as to involve as many people as possible (people with dementia, carers, families, friends or anyone with an interest in dementia) to take part, remain connected in their communities and participate in an enjoyable and stimulating meaningful activity. Doing so aims to build confidence in attendees, boosting their social skills but also to break down barriers for people with dementia, challenging stigmatising attitudes and assumptions about what a person with dementia can achieve. During one session in the Aberdeenshire group, an inspector from the social care regulator came along to one of the music groups and praised the involvement of people in sessions and the uplifting atmosphere created by the session.

Another specific project based in our Aberdeen Resource Centre saw a HCPC-registered Music Therapist work with people in both individual and group sessions, allowing them to sing, play instruments and listen to music, depending on their preferences and ability. This allowed the development of the person's skills, confidence and mood over a period of weeks. In this particular case, the service was delivered for both older and younger people with dementia, providing support personalised to each person, including their different tastes in music and preferences for instruments/vocals etc.

Even within group settings it is important for those running to the group to understand the individuals within the group; a standardised approach to such sessions is unlikely to provide maximum benefit to participants and may result in individuals taking part becoming agitated or stressed. From their own practice, our colleagues have shared that often small details such as the order songs are placed in, can drastically affect the experience of the person with dementia and the outcomes of such a music-based intervention.

Emerging Opportunities

As the number of people with dementia continues to rise and with an increasing number of people living longer with the condition, it is important to ensure that people are supported in a holistic way which supports them to live as well as possible with the condition. Alzheimer Scotland supports the development and delivery of new ways of working which recognise the importance of therapeutic interventions (including music-based interventions) as a crucial component. As we have noted above, music-based supports are flexible in the way in which they are delivered, being tailored for group or individual sessions. These include:

- A [pilot of Enhanced Sensory Day Care](#) for people with advanced dementia, including music as a therapeutic intervention. The pilot was evaluated by the University of the West of Scotland.
- Alzheimer Scotland's [8 Pillars Model of Community Support](#) and [Advanced Dementia Practice Model](#) both highlight the importance of therapeutic interventions as a key component of a holistic approach to care and support for a person with dementia. The former was tested as part of the second National Dementia Strategy (2013-16), with the latter due to be tested as part of the third (2017-2020).

Additionally, in Scotland, Self-Directed Support (SDS) legislation was passed in 2013 which aimed to improve the lives of people who use social care services by embedding a human-rights based approach, to give people greater choice and control over the supports and services they access. This includes the option of Direct Payments which, under the provisions of the legislation, allow people to choose how they are supported and on what the money is spent. However, the uptake and implementation of this policy remains low.

These policy areas and models represent just a few of the opportunities which have the potential to radically transform the way in which people are supported, shifting the emphasis away from formal and often institution-based interventions, to social and therapeutic interventions based in the community.

Barriers to Uptake

One of the key barriers in the uptake and delivery of formal Musical Therapy interventions is a shortage of empirical evidence to demonstrate the long-term benefits of music in improving

the wellbeing and quality of life of people with dementia. As a result, commissioners and decision-makers are less likely to commission such interventions without evidence of the improved outcomes for individuals. Whilst there is much anecdotal support for musical interventions in the broadest sense and some small-scale work and case studies, the shortage of empirical, peer-reviewed research means its benefit is not always recognised.

In Scotland, the variation in provision of supports and services between the Health Boards and Local Authorities (and more recently Integrated Joint Boards), has created variations in the provision of both health and social care supports and services. Music Therapy is resource intensive and, without the solid evidence base, is rarely funded by statutory organisations. It is beyond the means of many individuals to fund this themselves, meaning generic musical interventions are used as they are easier to deliver and more flexible, based on the time and resource of the context in which it is being delivered (i.e. whether by a local service, community group or by an unpaid carer etc.).

If music-based interventions are to become more widely available and embedded as part of holistic supports and services, a solid evidence base must be built to rigorously evaluate their effectiveness and benefit. Whilst the feedback from people with dementia, their families, carers and professionals is invariably positive, it would be helpful to have a robust evidence base which demonstrates:

- Reduction in stressed/distressed behaviours (including any associated reduction in medication).
- Improved mood and responsiveness in a person with dementia.
- Improved quality of life (possibly using wellbeing scales) for both people with dementia and their carers.

In Scotland, there are a number of policies for health and social care which have set out ambitious and commendable visions for a rights-based, person-centred system which is delivered seamlessly from the point of view of people using services. Condition specific strategies such as Scotland's National Dementia Strategies, legislation such as the Social Care (Self-Directed Support) (Scotland) Act 2013 and the new National Health and Social Care Standards, all intend to help drive a shift toward improving outcomes for the individual.

However, Alzheimer Scotland's experience of working with people with dementia, their families and carers suggests the policies are not always being realised in practice. It is our experience that transformational system change and service redesign has not taken place across health and social care settings; in some instances, temporary funding has allowed for pilots of new ways of working, however, services often revert back to the status quo once funding ends.

Alzheimer Scotland is aware of this having taken place in relation to funding through Reshaping Care for Older People, the Integrated Care Fund and other programmes of work which did not continue following the initial pilot work. Whilst appreciating that these short-term funding

streams are intended as a catalyst for system redesign and trying new ways of working, even where success is demonstrated, mainstream funding can be difficult to secure.

Aligning Interventions with Other Work

If Music Therapy and other musical interventions are to be recognised, valued and embedded as important supports to improve the wellbeing of people with dementia, their families and carers, it will require significant local investment in community-based, social supports and a broader recognition about the improvements in quality of life they bring.

Alzheimer Scotland has supported the development and publication of resources which demonstrate the work of AHPs, including Music Therapists, in supporting and improving the lives of people with dementia, their families and carers in different settings and environments:

- [Allied Health Professionals Dementia Champions: Agents of Change](#) - features practice examples provided by some of the AHP Dementia Champions.
- [Allied Health Professionals Delivering Integrated Care: Living Well with Community Support](#) – features the vital role of AHPs in delivering of integrated care, support and treatment for people with dementia.

Whilst the Scottish Government's [third National Dementia Strategy \(2017-2020\)](#) does not explicitly mention musical interventions, there are multiple references to the importance of therapeutic interventions for people with dementia, their families and carers. As part of this, there is a commitment to implement the Connecting People, Connecting Support work for Allied Health Professionals as part of the previous dementia strategy. This represents a considerable opportunity to promote and further raise awareness of the way AHPs, including Music Therapists, can support and deliver therapeutic interventions. Alzheimer Scotland supports a National AHP Consultant to deliver this work and work with other organisations such as the British Association of Music Therapists (BAMT).

As part of this work, Alzheimer Scotland has been working in partnership with the Music Therapy profession in Scotland, delivering the Alzheimer Scotland AHP Practice Education Programme. This partnership approach aims to give students the opportunity to experience working with people living with dementia, their families and carers. One element of this work included working with Queen Margaret University in supporting practice placements in Alzheimer Scotland services, including a music therapy intern in one of our services.

Influence and Delivery

Alzheimer Scotland believes no specific organisation should have sole responsibility for delivering musical interventions, with a collaborative effort required between organisations to ensure that robust, evidence-based policy and practice are embedded to utilise music-based

interventions and Music Therapy to improve the wellbeing of people with dementia, their families and carers.

Doing so will require further work to build a credible evidence-base which clearly demonstrates the benefits of the intervention to commissioners, policy makers and decision makers. Without this evidence base, it will be difficult to ensure that the benefits of musical interventions are recognised and seen as an important component of supporting people to live well with the condition.

Furthermore, in looking to promote this work and deliver a strong message about the effectiveness of this intervention, the Commission must look to involve people with dementia, their families and carers. People with dementia, their families and carers can more powerfully articulate the benefits of musical interventions and the effect it has on them better than any organisation or professional. As part of its work in this area, the Commission must look to engage with people with dementia, their families and carers to hear their experiences and insights, then develop their report and recommendations to reflect what matters most to them.

Messaging

It is Alzheimer Scotland's experience that social supports and therapeutic interventions are not valued in the same way as more traditional, medical-led clinical interventions. Social supports and therapeutic interventions, including those involving music, singing and sound are absolutely essential to ensure the wellbeing of people with dementia, their families and carers. The value of all forms of musical interventions should be recognised as being beneficial to the people dementia and their carers, with therapeutic interventions having equal importance to more traditional, clinical interventions. It is too often the case that therapeutic interventions and social supports are subject to short-term funding and are the first to be cut where resources and budgets are under pressure.

As part of the Commission's messaging on music and dementia, these points must be made strongly to ensure that policy makers, commissioners and decision makers understand the importance and effectiveness of these forms of support, properly investing and embedding these supports.

Alzheimer Scotland is happy for this submission to be made available in the public domain and a copy will be posted on our website.

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