



DEMENTIA CARER VOICES

people at the centre

Rights and the Carer Voice

**People
at the centre**

**Listening
with the heart**

**Caring
with compassion**



Artwork by Catalan artist Eloi Laporta

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Foreword



Irene Oldfather, Director The ALLIANCE

This publication represents a range of work carried out by Dementia Carer Voices over recent years, but in particular it undertakes a first analysis of our ‘You Can Make a Difference’ campaign, led by UK Project Engagement Lead, Tommy Whitelaw.

We have partnered with the NHS NSS, who have analysed the pledges we have received from Health and Social Care professionals and students and identified key emerging themes from what they freely wrote on their pledge cards. The ALLIANCE is incredibly grateful to the NHS NSS for the fantastic work they have done on the data analysis, especially to Themina Mohammed, who has contributed with her time and knowledge to help us analyse the pledges.

The publication is an example of true partnership, working not just with the NHS NSS, but also with the health and social care staff and students who have responded by making a pledge to make a difference. We are also extremely grateful to our volunteer, Celia Moreno, who spent hours inputting the data, and to our Administrator, Laura McCulloch, who works tirelessly to make the work we do possible. Finally, thanks to Tommy who tours the country creating a social movement for change in the treatment and care of people living with dementia.

Tommy Whitelaw, UK Engagement Lead, The ALLIANCE

I would just like to say a massive thank you to the health and social care staff and students who make the work of ‘You Can Make a Difference’ possible. Thanks for the wonderful work they do every day caring for the most vulnerable people in our society and for taking the time to make the pledges that they make.

“It is a true privilege to get to meet these inspiring people at the front line of our health and social care system every day and to share the stories of unpaid carers, both my own and those from the letters I receive.”

I would like to thank the great Dementia Carer Voices team, Irene Oldfather, Laura McCulloch and William Kløverød Griffiths. Also a special thank you to Ian Welsh, Chief Executive at the ALLIANCE, Fiona McQueen, CNO Scotland, Jane Cummings, CNO England and a personal thanks to First Minister, Nicola Sturgeon. Without their support we would not be able to do what we do.

To every single person who has made a pledge to make a difference - Thank You!

Paul Gray, Chief Executive, NHS Scotland

We are hearing from individuals about what they think they can do.

I think the emphasis there on that wording – “you can make a difference” – the first word is: “you”. That means people, individuals, can make a difference. And the second word is “can”. It is within our grasp to make a difference and I think it’s really important that we realise this.

I also think that, from my perspective, I need to listen to the voices of carers, because in my life experience I have not been a carer so I can’t say that I know what it would be like to do that, and that’s why I think it is hugely important that I listen to and learn from the real experiences of carers.

I wish you every success with your endeavours. I think you’re creating a real impetus behind this programme and I think it will be of benefit to the people of Scotland and I think the wider international community are interested in what we’re doing.

I think it’s really important that we are demonstrating top class practice and hearing the voices of care and making changes as a result. And I just want to assure all our staff of NHS Scotland that I am completely supportive of them giving their testimony as to what they will do in relation to this programme.

So, to me, it’s about hearing voices and answering to those voices that we hear.

Dementia Carer Voices

Rights and the Carer Voice



Dementia Carer Voices is a programme of work funded to engage with health and social care staff and students to promote a fuller understanding of the carer journey and provide a platform where carers can express their views and experiences caring for a loved one with dementia.

Dementia Carer Voices is managed by the Health and Social Care Alliance Scotland (The ALLIANCE) and aims to:

- Capture the experiences of carers across Scotland with a view to informing future policy and service provision;
- Raise awareness of the issues around caring for someone with dementia including among health and social care professionals, students and the wider public;
- Highlight the role of carers as experts, who should be recognised for the value that they bring to the life of their loved ones and to society as a whole.
- Empower carers by providing information based on the Charter of Rights and Carers Strategy about caring for someone with dementia.

During the time in which Dementia Carer Voices has been running, the Scottish Government has progressed with Dementia Strategies One, Two and is about to publish Dementia Strategy Three. It is into this Policy Context¹ that Dementia Carer Voices fits; as part of the Scottish Government's move to improve the quality of life for people with dementia, their families and carers. Since it was started in 2012 Dementia Carer Voices has sought to represent the voices of people with dementia and carers, ensure their interests are reflected in policy and promote a rights based approach.

The Five 'Must Do With Me' Steps

- What matters to you?
- Who matters to you?
- What information do you need?
- Nothing about me without me!
- Service Flexibility.

What Matters to You?



Illustration by Michaela Tait (@michaelafinegan)

1. For an overview of the Policy Context, see Appendix 1.

Overview of Dementia Carer Voices Activity

Letters from Carers Publication

As part of the work of capturing the lived experience of carers Dementia Carer Voices partnered with academics at the University of Glasgow in 2015 to analyse 400 of the letters Tommy has received from unpaid carers since he started sharing his experience of caring for his mum, Joan.

The publication by Irene Oldfather, Tommy Whitelaw, Jane Joy and Diane Willis was published in the International Journal of Ageing and Society based at the University of Illinois in March 2016.

The key findings were:

- The loneliness and isolation of caring;
- The frustrations involved in caring;
- The economic challenges of caring;
- The patchwork of care and support available.

Joy, J., Whitelaw, T., Oldfather, I. & Willis, D., (2016) [People with Dementia and their Carers' Experiences.](#)



International Journal of Aging and Society.

Letters, Life and Love Stories - A Celebration of Caring in Scotland



The 'Letters, Lives and Love Stories' concert, held in Glasgow's Royal Concert Hall on the 20th January 2014, was a part of the Celtic Connections Festival and

offered an opportunity to celebrate carers. Ahead of the concert, then Deputy First Minister Nicola Sturgeon addressed the audience of 500 specially invited guests, reminding the audience of the important role that carers play in the lives of people in Scotland. Invited guests included carers, nurses, occupational therapist, physiotherapists, care assistants and volunteers.

Carers from across Scotland were invited to share what caring means to them by adding their leaf to the 'Letters, Lives and Love Stories Tree'. The key motivations which emerged were love, dedication and the rewarding nature of caring. Carers also took the opportunity to highlight the importance of support, the emotional impact of caring and the often unappreciated role of a carer.

"Caring means good times and really hard times. We do it because we love."

"Caring means to listen without judgement and support unconditionally."

"Making sure our lives are happy ones"

Rights, Dignity and Respect

In 2009 Scottish Parliament Cross Party Group on Alzheimer's working in partnership with the Scottish Human Rights Commissioner and Alzheimer Scotland asked people with dementia and their carers across Scotland about the challenges and barriers of living with dementia and what could be put in place to support and empower them to live well.



From the hundreds of responses, the 'Charter of Rights for People with Dementia and their Carers in Scotland' was constructed and presented to Parliament in October 2009. Following debate on Motion S3M-4852 in the name of Irene Oldfather, all political parties agreed to the motion.



"Human rights have to be meaningful to an individual. Being person centred and discovering what matters to them is at the heart of human rights."

Caroline, who cared for her mum, Kitty

The ALLIANCE supports the objectives of the Charter of Rights for People with Dementia and their Carers which adheres to the PANEL approach to Carers Rights – that is that carers of people with dementia have the right to:

- o Participate in decisions which affect their human rights;
- o Accountability of those responsible for the respect, protection and fulfilment of human rights;
- o Non Discrimination and equality;
- o Empowerment to know their rights and how to claim them;
- o Legality in all decisions through a explicit link between human rights and legal standards in all processes and outcome measurements.

"On rights it's time to move from rhetoric to reality, everyone needs to know the PANEL principles and to ensure that they are in place for every person, every time"

**Irene Oldfather,
ALLIANCE Director**

Producing the Charter of Rights

The Charter of Rights was co-produced with people with dementia and their carers in a series of roadshows across Scotland starting in Irvine and organised by Alzheimer Scotland which asked about the challenges and barriers which people faced in their day to day lives.

The results were analysed with the help of Alzheimer Scotland and the Scottish Human Rights Commissioner, Professor Alan Miller, who dedicated a small team to producing a Charter which would be understood and claimed by people with dementia and their carers. Since the Charter of Rights passed in 2009, Rights Based approaches to health and social care have become more prominent. The Charter itself is embedded into the National Dementia Strategy and the SPSO has benchmarked against the Charter.

Motion S3M-4852 approved by the Scottish Parliament in October 2009

“That the Parliament welcomes the principle of a charter of rights for people with dementia, as proposed by the Cross-Party Group on Alzheimer’s; believes that changing attitudes and practices that deny people with dementia their rights is a major challenge facing health and social care groups; notes the recent publication of a number of reports that have highlighted the inefficiencies in the quality of care for people with dementia in the community, in care homes and in long-term hospital care, including the Care Commission report, Better care, every step of the way, and the joint report by the Care Commission and Mental Welfare Commission for Scotland, Remember, I’m Still Me; notes the consultation undertaken over the summer to

give people with dementia, their carers, health professionals and care home staff, among other stakeholders, an opportunity to express their views on the issues that they believe a charter should address; welcomes the commitment of Alzheimer Scotland to enable stakeholders to participate by organising roadshows in Irvine, Glasgow, Edinburgh, Dundee and Inverness; acknowledges that the charter of rights is based on internationally agreed human rights and is intended to promote the respect, protection and fulfilment of all human rights of people with dementia and their carers, and therefore welcomes the idea of a charter as both an instrument for enabling culture change and as a tool to empower people with dementia.”



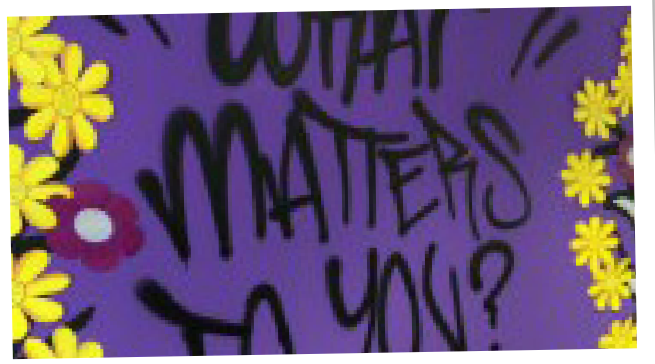
The Charter of Rights was unanimously approved by MSPs in October 2009

You Can Make a Difference

In February 2014, the ALLIANCE'S Dementia Carer Voices' project initiated the '[You Can Make a Difference](#)' campaign which uses Value Based Reflective Practice to raise awareness and engage with Health and Social Care students and professionals across the UK. Since that time UK Engagement Lead, Tommy Whitelaw has taken the story of caring for his mum Joan to the heart of the NHS and local communities. In doing so he has inspired and motivated the over 85,000 people that he has engaged with and collected over [14,000 pledges](#) to make a difference to the lives of people with dementia and their families.



By looking first at what staff and students would like to do to make a difference, and then looking at the barriers they perceive in their working lives, the data analysis presents a picture of the factors which impact on providing good care to people living with dementia and also gives an insight into what needs to happen to drive culture change and person centred care in the health and social care system.



In June 2016 Dementia Carer Voices partnered with NHS NSS to perform analysis work on the pledges received. In order to undertake the analysis NHS NSS used 6,000 pledges to identify the most common themes in the responses of health and social care staff and students. The pledges are the personal commitments of the staff and students hearing the personal story of an unpaid carer and as such provide a valuable insight into the views, concerns and motivations of those who work, or will work in the health and social care profession.

Health and social care staff and students are also asked to comment on what barriers they anticipate facing in fulfilling their pledges. The analysis of barriers provides a valuable insight into the potential problems that the audience face in providing the quality of care to which they aspire in fulfilling their pledges.



['You Can Make a Difference'](#)
[Case Studies](#)

Our Pledges

"I pledge to listen with open ears and an open heart."

"I pledge to view the person I care for as all that they have been, they are and all that they can be."

"I pledge to take the time to speak to the person's family and provide support to make their lives as fulfilling as possible."



"...as long as I've got any influence in government, my pledge is to help people who are working hard to make life better for people living with dementia"

**Nicola Sturgeon,
First Minister**



"As an unpaid but proud and privileged carer I pledge to always hear and listen to the carer voice"

**Ian Welsh,
CEO,
The ALLIANCE**



"Advancing the rights of people with dementia, and their carers who sometimes face extraordinary challenges and barriers in communicating their needs and wishes, is a just cause. By harnessing the power of carers' lived experiences, the You Can Make a Difference campaign speaks to the hearts of people and communities across Scotland, with the simple message that dementia is everyone's business and that you have the power to transform the experiences of people affected by the condition."

**Irene Oldfather,
ALLIANCE Director**



"Carers tell us that a little bit of time, listening and understanding can make an unimaginable difference during what can be a very difficult and lonely journey. No matter what your role, you have the potential to

transform the lives and experiences of people with dementia and their carers."

**Tommy Whitelaw,
UK Engagement Lead**



A You Can Make a Difference pledge tree at Focus on Dementia's learning session in April 2017

Tommy's Story



My name is Tommy Whitelaw, and for five years I was a full-time carer for my mum Joan, up until she sadly passed away in September 2012.

At the time my Mum was diagnosed with vascular dementia, I looked at her and thought to myself **"it'll be okay, we'll get through this."** What I soon learned as her carer, was that dementia was an unpredictable illness which brought many challenges and forced us to adapt to ever-changing routines. Many days we would wake up to discover that everything we had grown accustomed to had suddenly changed again.

I wondered whether the struggles I faced were mine and mine alone, and how other carers who had been through the same journey that I was embarking on, had managed to cope. This was the basis behind my first venture into the world of awareness raising – the 'Tommy On Tour' campaign, which involved collecting life story letters from people across Scotland caring for a loved one with dementia.

The hundreds of letters I received let me know that the challenges I faced were far from unique to my own situation and I have to say meeting

and speaking to others in the same situation was one of the most beneficial things I could have done.

An issue that struck me during my journey caring for my mum was the lack of awareness and understanding of dementia and the way in which we perceive this illness as a wider society. My door was always open but no one walked through it, people didn't come to visit us anymore and I truly believe that was down to the stigma surrounding the illness.

Everyone affected by dementia has a unique story to tell and by sharing our experiences we can help to tackle the misunderstandings surrounding dementia and offer hope to people in the same situation. This is something I am passionate about promoting as I build on my previous awareness raising work, as UK Engagement Lead of the Health and Social Care ALLIANCE's Dementia Carer Voices Project.

The project provides a platform upon which carers can express their views and experiences of caring for a loved one living with dementia, with a view to raising awareness among health and social care professionals, and wider society of its impact on families and the importance of empowering carers in carrying out this difficult but vital role.

A key focus of my talks through the project is to highlight the impact that inspirational health and social care professionals can make to the journeys of carers across UK. People who appreciate and understand the unique challenges that dementia brings can be there to prop you up, and I absolutely believe as a carer if I was propped up a little bit with the right help and support, I could have given my Mum the best care and support in the world.

The experience of caring for my Mum undoubtedly brought great challenges, stress, isolation and sadness, but it was a role carried out through love and we enjoyed many touching moments of joy and satisfaction. Those special moments live long in my memory, and gave me a real boost of strength to get through the difficult times, and continue to do so now.

Analysis of the Pledges

Using the principles of value based reflective practice, Tommy’s presentation seeks to engage with health and social care professionals and students to encourage them to reflect on how they can make a difference to people with dementia, their families and carers. Taking his story to 85,000 health and social care professionals, Tommy has collected 14,000 pledges from his audiences in over 600 locations.

In partnership with NHS NSS a data analysis of 6,270 of these pledges was undertaken and key emerging themes were identified from what the health and social care professionals and students wrote on their pledge cards.² This resulted in identification of the five most common pledge types across the datasets, the most common barriers to fulfilling pledges, differences between nurses and student nurses and differences between Scotland and England.³

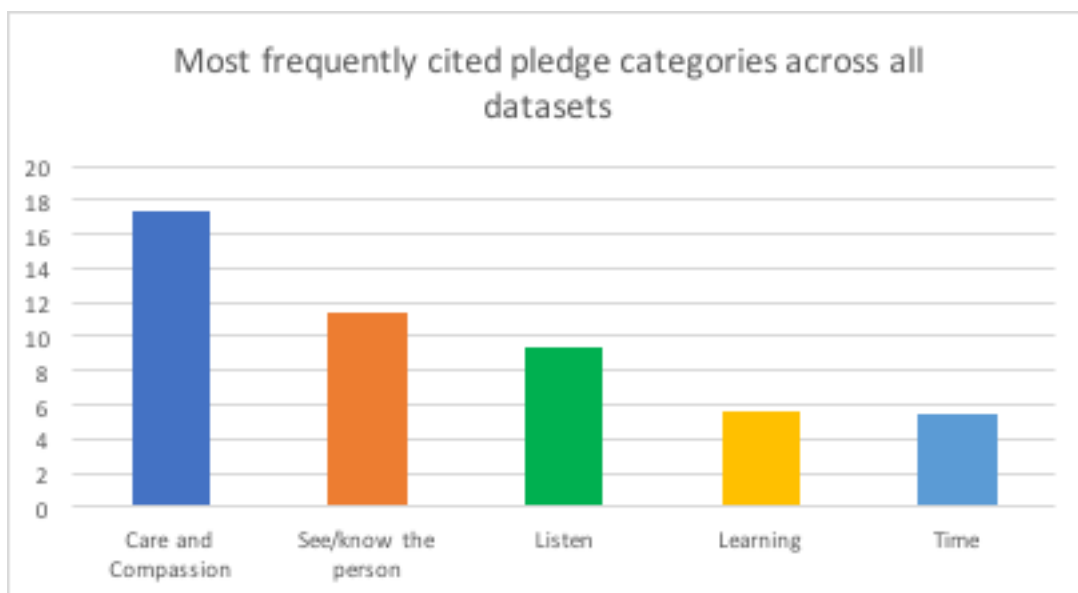


Figure 1 shows the percentage of pledges in each category across the datasets – Care and Compassion N3,565, See/Know the person N2,342, Listen N1,909, Learning N1,151, Time N1,115. (y-axis is the percentage of pledges, x-axis is type of pledge made)



Image created by NHS NSS.

2. See Appendix 2 for more details.
 3. Those who made a pledge could mention several characteristics within one pledge. Therefore, there is an element of double counting. For example, some people mentioned listening and care and compassion in their pledge and this pledge is counted in both categories.

Figure 1 shows the five most common pledge types across all countries and groups. Care and compassion (N3,565) stood out above all other areas. Since the Mid Staffordshire NHS Foundation Trust scandal and the Mental Welfare Commission report Dignity and Respect compassionate nursing has been a central plank of focus of the NHS in both Scotland and England. The presentations therefore are clearly aligned to the future policy direction of the two countries.

It was encouraging that 'seeing/knowing the person' (N2,342) came across so strongly, as this is one of the key themes which the presentations seek to emphasise. N1,909 pledges referred to listening to people with dementia and their families, this is very much in line with Dementia Carer Voices promotion of key listening methods, and on the basis of these high numbers it has been decided that future presentations will include the Active Listening model. The final two most common pledges are around learning more about dementia and understanding of how to make a difference (N1,151) and making time in busy schedules (N1,115).



The pledges received are person centred and heartfelt and represent the good intentions of health and social care professionals and students to make a personal difference to people with dementia and their families across all care settings. Although individual in nature their collective impact is to raise awareness, create constructive conversations and in fulfilling these good intentions begins to create a movement for social and cultural change.

Four principles of Active Listening

Active listening is a communication technique that requires the listener to fully concentrate, understand, respond and remember what is being said. This type of listening is encouraged in counselling, training, and conflict resolution, and is opposed to reflective listening where the listener repeats back what the speaker has said just to confirm both parties understand what is meant.

The key techniques of Active Listening are:

1. Empathic Listening.
2. Comprehensive Listening
3. Critical Listening
4. Appreciative Listening

<http://www.central.knowledge.scot.nhs.uk/Leadership/active-listening.html>

Key messages:

- Following difficulties evidenced by scrutiny reports, encouragingly care and compassion emerges as a key plank of awareness raising;
- The Active Listening model could provide a useful tool to support and empower health and social care professionals and students.

The Most Common Pledge Types

Care and Compassion

- "My pledge is to look after each of my patients individually. I promise to always treat my patients with care and compassion";
- "My pledge to do what I can, with kindness, love and compassion";
- "I pledge to always treat people in my care as individuals and with respect and compassion."

Listen

- "I pledge to listen more carefully to people around me because everyone has a story to tell."
- "I pledge to hold your hand, listen to your stories, help and guide you when needed and always remember you have a name."
- "Talk and listen to my residents with dementia in an open and engaging way."

See/Know the Person

- "I pledge to always find out what really matters to my patients and their carers."
- "I pledge to continue to see the person and their story as what defines them, rather than the illness, and to treat each individual and their family in the way I would want my family to be cared for."
- "I pledge to see the person behind the patient and keep the love story going for that person and the people close to that person"

Learning

- "I pledge that I will promote an understanding of dementia with my family, friends, colleagues and the general public who I come across in my work role"
- "I hope to pass on my knowledge and understanding of dementia when and where it may be needed."
- "I pledge that I will give my all and take the information I have learned."

Time

- "I pledge that I will take the time to consider the perceptions of patients with dementia and their families/carers."
- "My pledge is to go the extra mile. Take time and stop to see how others (Family & Friends) are doing and remember the dementia isn't the person behind it."
- "I pledge to make as much time as possible, however small and to make someone smile every day."

Barriers to Fulfilling a Pledge

As part of the pledge health and social care staff and students are encouraged to reflect on what barriers they may face in fulfilling their pledges. It is interesting to note that 45% said nothing

would prevent them fulfilling their pledge at the time of making it. This is encouraging and demonstrates a high degree of motivation from a clearly caring and compassionate workforce.

Most frequently cited barriers across all datasets

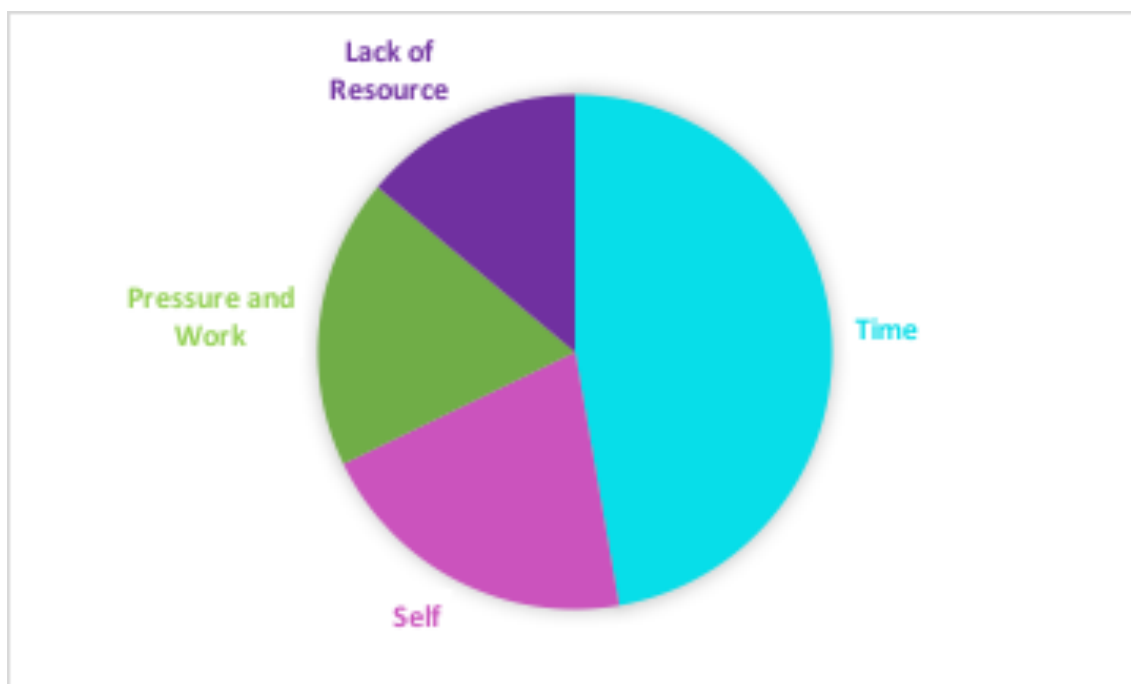


Figure 2 shows the percentage of barriers identified across the datasets – numbers: Time N886, Self N386, Pressure and Work N342 and Lack of Resource N261. Of the N4,333 barriers to fulfilling the pledge, N1,960 (45.2%) reported that nothing would stop them, as this number was so significant it was separated.

However, of those who did identify a barrier the most common was time (N886). In addition to those who mentioned time, pressure and work (N342) and lack of resource (N261) were some of the major barriers identified as preventing people from fulfilling a pledge. If truly focused person centred care is to be achieved, it is important that the views of health and social care professionals and students are listened to. While it is encouraging that most staff and students do not identify a barrier, over a third identify issues related to resources as preventing them from fulfilling their pledge.

In relation to both the positive nature of pledges and the negative nature of pledges it is clear that there is a disconnect which reflects time and task oriented care. In order to be truly person centred care, compassion and conversations have to be at the heart of delivering health and social care.

Reading through pledges relating to self, it is evident that self doubt is a factor in people’s assessment of their ability to maintain their pledge. For example, in terms of identifying barriers, one nurse commented **“myself and losing focus”** and another said **“only my own shortcomings”**. In order to resolve these issues, not only will confidence and support be required, but also strong leadership.



The 'You Can Make a Difference' campaign has received pledges from the most senior sections of Government, including First Minister, Nicola Sturgeon, Chief Nursing Officer Fiona McQueen and NHS Scotland CEO, Paul Gray. To make the necessary shift to bring about change, leaders across not just the NHS, but health and social care partnerships will need to take ownership

of this agenda to ensure the necessary steps are taken to achieve change in thinking, change in practice and change in behaviour and to support and empower health and social care professionals to achieve their pledges.

Key messages:

- It is really important to move away from a time and task culture to one that places care and compassion at the heart of how we look after people with dementia;
- Empowering and supporting staff across a range of settings is vital to achieving a culture change;
- Strong leadership is an essential component of the transformational change needed to support staff.

Examples of the most common barrier types:

TIME

- "The workload and time."
- "Time! Not having the time to show the compassion I hope to show by becoming a nurse."
- "Time pressures of work and life."

PRESSURE AND WORK

- Pressure of work, limited time allowed to really getting to know people."
- "Pressure put on nurses in the ward environment"
- "Paperwork pressures."

SELF

- "Myself and losing focus."
- "If I was struggling myself for some reason. Need to look after ourselves to be able to care for others."
- "Only my own short comings. Nobody can stop you being kind."

LACK OF RESOURCE

- "Not being allowed to help through lack of resources."
- "Lack of time, resources. Chronic stress causing me to not to be as passionate as I can be, would like to be due to lack of resources."
- "Lack of staff in the community."

Differences between nurses and student nurses, Scotland and England

In reviewing the analysis in relation to the difference between nurses, student nurses, Scotland and England, it became apparent that there were no significant differences in relation to the pledges made. Of the 6,270 pledges, N3,669 were from student nurses and N1,473 were from nurses. This represents a large proportion of the pledges made due to the fact that Tommy usually addresses audiences in hospitals, care homes, universities and colleges. As a result, the most common audiences and those who make pledges are nurses and student nurses.



For nurses and student nurses, care and compassion remains the most common pledge type (N763 and N2,082 respectively). Nurses and student nurses also frequently emphasise the importance of a good conversation and learning what matters to the person for whom they care. This suggests that nurses and student nurses are on board with the lessons from 'Active Listening' and that they are invested in genuinely listening to the answers they receive and hearing from the heart.

In relation to barriers, it is noteworthy that while student nurses and nurses were in the main reflecting similar views, many more student nurse perceived time as a barrier than nurses. This has clear implications for Senior Managers and universities who must look to support student nurses in removing barriers to the compassionate Person Centred care that they want to deliver.

When examining the differences between Scotland and England the pledge data shows that health and social care staff and students have similar priorities in the two countries. The overall differences are small, with care and compassion, listening and seeing/knowing the person being the most common themes emerging.

Looking at this data it suggests that in both countries the pledges are of a very personal nature. The pledges come from the heart, and despite differences in the policy landscape in which staff are working between Scotland and England, the headline numbers share the core theme of being deeply personal in nature.

Between the two counties the differences in pledge data present shades of similar attitudes that the health and social care staff and students bring to their pledges. This suggests they are less moved by the policy landscape in which they operate and more by the personal nature of their work and power of the lived experience of the presentations. A similar picture emerges in an analysis of the barriers across Scotland and England. Again, the differences are small.



Time for Reflection

Following presentations, Dementia Carer Voices received a large amount of communications (email, letters and twitter) regarding the content and nature of the presentation. These communications are useful, because, although they are fewer in number than the pledges and barriers, they are completely open ended

and therefore present a unique opportunity to consider in more detail the lived experience of those responding.

From 600 presentations, qualitative analysis of a random sample of responses (N70 approx.) identifies a number of key themes.

Reconnecting with Values

"I was thinking about leaving nursing, but your talk made me remember why I wanted to be a nurse, I want to make a difference."

This is one of the most common types of feedback Tommy receives in letters sent to him after his talks. Health and social care staff write him to say that they were on the brink of giving up the profession or taking early retirement and that his talks reminded them why they went into nursing in the first place.

A high turnover of staff can make it hard for care homes and care at home providers to give high quality, consistent and person centred care. It is therefore important to encourage staff to reconnect with values of the profession.

It is widely accepted that familiarity and routine can assist in managing the symptoms of dementia, but a lack of continuity in staffing is reported by many families as a barrier to good, consistent and high quality care.

"There is a shortage of staff – people are brought in who don't know the conditions of the service users they are caring for."

Care home staff member

Esteem in the profession

"After your talk, I feel even more proud to broadcast that I am a student nurse"

An issue of self-esteem is often prevalent in the letters Tommy receives. Some express that they feel society does not value the work that they do and that, as such, they feel undervalued in the role they perform.

It is frequently reported by carers that pay and conditions of service do not adequately reflect the importance of the work of the caring for the most vulnerable in our society.

It is encouraging that when listening to the carer voice, nurses, student nurses and others in the caring profession clearly feel a sense of pride in what they do. Valuing and supporting those who look after the most vulnerable in our society will require strong leadership from the highest levels across all levels.

Understanding People Living with Dementia

"I have never felt so positive about dementia after listening to today's presentation."

It is important to increase knowledge and understanding of what it's like for people with dementia and their families. Part of the clear learning from this is the importance of seeing the person and not the condition.

In order to deliver real person-centred care, it is important that staff know as much as possible about the lives, personalities, likes and dislikes of the people for whom they care and what matters to them. This enables staff to give care and treatment which is individual and not task oriented.

Recording life history information and understanding how a person lived before they developed dementia helps staff to appreciate how the person's past affects their present life and behaviour, individualise the care of the person and help maintain their identity. There are several person centred approaches which focus on the importance of conversations and assist staff to have a framework around which to take forward discussions about future planning, health and well being, such as 'What Matters to you?', House of Care and Alzheimer Scotland's Pillar Approach.

"I look at the person with dementia and think 'I wonder what she did in the past.' If we knew it might make some of us feel a little bit ashamed of seeing the dementia first and not the person."

Nurse

Constructive Conversations with Carers

"I know my mum best. It matters that people take the time to ask about her as a person."

Carer

One of the main focuses of the 'You Can Make a Difference' presentations and the work Dementia Carer Voices is to emphasise the role that carers and families can have in supporting staff to care for and connect people with dementia to their environment and communities.

Listening to the voice of carers would allow people with dementia to be better connected to care homes, care at home or other supported environments. Carers can further provide vital information and support during hospital admission or investigation which can be very disorienting for a person with dementia.

"Thanks to your story with our staff we have done reflective writing on what we learned and how we can move forward to improve the quality of life of our residents living with dementia."

The **"Promoting Excellence"** framework has set out clearly the importance and value of carers and family as an integral part of a holistic approach to health and well being of people with dementia. The Scottish Government's Equal Partners in Care similarly recognises the role of carers and families. Despite this backdrop, many carers still feel that their views on the care of the person with dementia are not sufficiently taken into consideration by health and social care professionals.

While some carers highlighted positive examples of being involved during a hospital stay e.g. helping with meals or personal care, others however, describe inconsistent approaches which varied from ward to ward and person to person.

Listening, Hearing, Acting

The current direction of travel, as captured in the Policy Context (Appendix 1), around shared decision making, the National Clinical Strategy, Health and Social Care Delivery, Realistic Medicine and the Dementia Strategies are a strong platform from which to build consistent high quality care. However, policy and process are not enough; there remains a gap between intention and implementation. Dementia Carer Voices, the Charter of Rights and the You Can Make a Difference campaign are important drivers in narrowing that gap, supporting staff and encouraging people to live the lives they want to live.

The key learnings from the voices of 14,000 health and social care staff, students and carers - from the quantitative analysis of pledges and barriers to the qualitative analysis of information received over the time span of the project - should not just be heard but should be acted upon.

Overview of Learnings

- Following difficulties evidenced by scrutiny reports, encouragingly care and compassion emerges as a key plank of awareness raising;
- The Active listening model could provide a useful tool to support and empower health and social care professionals and students.
- It is really important to move away from a time and task culture to one that places care and compassion at the heart of how we look after people with dementia;
- Empowering and supporting staff across a range of settings is vital to achieving a culture change;
- Strong leadership is an essential component of the transformational change needed to support staff.
- Time perceived as a significant barrier for delivering genuinely person centred care;
- Personal nature of pledges relates more to the lived experience than differences in the policy landscape.
- Ensuring that everyone who works with people living with dementia practices rights based approaches based on the Charter of Rights and the PANEL approach.



Appendix 1: The Policy Context

There has been an explicit focus on tackling dementia in policy in Scotland. As a result of this demographic change it is predicted that the number of people with dementia in Scotland will rise from around 90,000 people today to 164,000 people in 2036. Since the publication of the first National Dementia Strategy there have been many publications and policy proposals aimed at improving the quality of care for people with dementia, their families and carers.



Christie Commission on the Future Delivery of Public Services (2010)¹

In 2010, the Christie Commission's report on the Future Delivery of Public Services set out the many challenges and opportunities that Scotland faces as a result of demographic changes and wider challenges facing public services.



Realistic Medicine²

The Chief Medical Officer's annual report, 'Realistic Medicine' (2016) argues that 'there is an imperative for a system and values change that rebalances decision-making

power, where the expertise of professionals is valued equally to the expertise that people have about themselves' and to move away from a paternalistic 'doctor knows best' model.



National Clinical Strategy

Published by the Scottish Government in February 2016, the 'National Clinical

Strategy' aims to provide clarity on the priorities for reform of healthcare in Scotland, making high level proposals for how clinical services need to change in order to ensure a sustainable model which is fit for the future.

The Health and Social Care Delivery Plan³

The Health and Social Care Delivery Plan of December 2016 set out an ambition of integrated working "so the people of Scotland can live longer, healthier lives at home or in a homely setting"

National Dementia Strategies⁴

In an international context, Scotland is considered to be ahead of the curve in terms of policy measures around dementia.

Dementia strategies One and Two focus on how to address five key challenges that need to be addressed to improve the lives of people with dementia, their families and carers. The Third National Dementia strategy will be published imminently. The direction of travel is likely to be around:

- a more flexible approach around post diagnostic support;
- continuing emphasis on early diagnosis;
- and emphasis on ensuring appropriate palliative and end of life care.

1. Commission on the Future of Public Service Delivery, 2010, <http://www.gov.scot/Resource/Doc/352649/0118638.pdf>

2. Chief Medical Officer's Annual Report 2014 -15, Realistic Medicine, <http://www.gov.scot/Resource/0049/00492520.pdf>, p.17

3. Scottish Government, 2016, The Health and Social Care Delivery Plan, p. 3 <http://www.gov.scot/Resource/0051/00511950.pdf>

4. Scottish Government, 2010, Scotland's National Dementia Strategy, <http://www.gov.scot/Resource/Doc/324377/0104420.pdf>

4. Scottish Government, 2013, Scotland's National Dementia Strategy: 2013-2016, <http://www.gov.scot/Resource/0042/00423472.pdf>

About NHS NSS



The NSS-ISD are supporting the Health and Social Care Integration agenda to help deliver high quality, effective and efficient services to meet the needs of changing populations. On the ground support in the form of Local Intelligence Support Team (LIST) are deployed to provide expert analytical and data management expertise. The LIST service provides local decision makers with meaningful and actionable intelligence, leading to improved outcomes for service users and patients.

The LIST team were asked to support the Dementia Carer Voices Pledge Project. Tommy Whitelaw from ALLIANCE asked LIST to review the data that had been collected in the form of free text pledges made using pledge cards. The aim was to create a structured method of collating the data electronically and then assist in data quality, and finally the data analysis.

LIST worked closely with the ALLIANCE team to produce an Excel based tool to capture the free text pledge data. LIST also provided training and support in using the tool. Once the data had keyed into the tool, the electronic file as then passed to LIST. The data file was then analysed and the findings were presented in the form of tables and charts for the Dementia Carer Voices Pledge Project.

Local Intelligence Support Team (LIST)

Website: www.isdscotland.org/localintelligencesupport

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About the ALLIANCE

The Health and Social Care Alliance Scotland (*the ALLIANCE*) is the national third sector intermediary for a range of health and social care organisations. It brings together over 1,800 members, including a large network of national and local third sector organisations, associates in the statutory and private sectors and individuals.

The ALLIANCE's vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims; we seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.

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DEMENTIA CARER VOICES

people at the centre

Rights and the Carer Voice



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To keep up to date with our latest activity, please visit:

www.dementiacarervoices.wordpress.com

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ALLIANCE
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