The Care Cameos series is designed to present short but challenging sketches of various issues and to provide a forum to encourage and foster debate on a whole range of issues important for the delivering of care and support for older individuals across Scotland.

#### **Scottish Care**

25 Barns Street Ayr, KA7 1XB Co. SC243076



# #careaboutcare

**SCOTTISH CARE BLOG HIGHLIGHTS 2017** 



PART OF THE CARE CAMEO SERIES







#### **Preface**

"Words have the potential to be one of the greatest resources available to humanity... Used well they have a unique energy and vitality, they have the ability to challenge and console, to soothe and inflame, to heal and to inspire."

Over the last year Scottish Care has published a range of blogs. They have been powerful examples of the ability of words to change, challenge, create and counsel. The blogs have covered a wide range of issues and themes and have provided compelling evidence of the astonishing range of care and support which is offered by the independent sector across Scotland.

A blog in essence is a short piece of writing, a set of words, which describes something of the moment; it is a snapshot of an experience, a depiction of a standpoint, the expression of an opinion, the presentation of a perspective. The truthfulness and authenticity of the blogs have been that they have been the honest words of those who work in care. They have been the words which are often not heard and perspectives rarely shared.

So, I am delighted that this short collection has sought to bring together some of the best and most widely read of the blogs of the last year. I hope as you read the words in the next few pages you will get something of the passion which is evident in social care across Scotland.

For many individuals having someone hear their voice, having a sense of being heard and valued for who they are is the essence of good social care and support. I hope that having read the words in this collection you will become a regular reader of the Scottish Care blogs. Those who share their insights, who place their words before you, deserve to be heard and probably more importantly those who are supported and cared for deserve to be recognised.

Enjoy the read.

# Dr Donald Macaskill CEO Scottish Care

### **About the Scottish Care blog series**

In 2016, Scottish Care began sharing blogs via our website (www. scottishcare.org) as a means of better sharing the work of the Scottish Care team, good practice examples from our member services and developments taking place in the social care sector. In 2017, the frequency of blogs was increased to weekly, with every second blog written by CEO Dr Donald Macaskill. Other contributors include members of the Scottish Care team, our members and colleagues from partner organisations.

The blogs have proven to be extremely popular and have been shared widely, as well as some being picked up by the media. They have provided a valuable avenue for Scottish Care to engage with our members and partners, and we hope that you have found them interesting to read.

Some blogs are written to share, others to challenge and others still to celebrate. Memorable moments from the year have included blogs shared as part of Care Home Week in June and Home Care Day in October. Many have also been linked to reports published by Scottish Care throughout the year, providing more insight and opinions on their findings. It has also been positive to share the work of Local Integration Leads and Development Officers, operating in health and social care partnerships to support the independent sector in integration and improvement activity.

The task of selecting blogs to feature in this Care Cameo was extremely difficult given that all of the 2017 blogs are worthy of inclusion. We therefore decided to choose a set of blogs which illustrate the range of contributions, issues and styles we have featured throughout the year.

We hope it inspires you to engage with or revisit more of the blogs, and to consider sharing your stories with us in 2018. We will continue to share blogs on the Scottish Care website and Twitter page on a weekly basis, and would love to hear from you!

## Carespotting

In January 2017, to coincide with the release of Trainspotting 2, the Scottish Care National team adapted the classic 'Choose Life' monologue from the film.

Choose life.

Choose meaningful partnership.

Choose human rights.

Choose difficult conversations.

Choose inclusion.

Choose learning.

Choose a rewarding career.

Choose achieving things you never thought you could.

Choose innovation.

Choose to be brave.

Choose to value the things that matter most, like people and relationships.

Choose living well.

Choose dying well.

Choose positive ageing.

Choose improvement.

Choose an extended family that never leaves you. Choose quality.

Choose a sustainable system, that's there for you when you're old and your kids after that.

Choose where you want to be, and who you want to be with.

Choose living to the full, right to the end.

Choose your future.
Choose life.

# Are all people living with a diagnosis of dementia treated equally?

Rene Rigby - Local Integration Lead, Edinburgh

There are thought to be around 650,000 people in the UK who are estimated to experience some degree of gender non-conformity (Gender Identity Research and Education Society).

It is widely recognised that there is limited evidence on the experiences of transgender people in Scotland and even less information regarding transgender people who have now developed Dementia.

For the first time, there is an ageing transgender population and as a result, many health and social care professionals are working with older transgender clients for the first time, many of whom have complex cognitive, social or bodily needs relating to their gender reassignment. We are only now seeing the first generation of transgender people in their 60s and over who have taken hormone therapy for 30 years or more, many of whom are living with gender reassignment surgeries performed using the very different techniques of the 1960s and 70s. Care is something that is often taken for granted. Illness and disability can occur without warning through accident or old age and the opportunity to arrange and to inform local caring services about their lifestyle or past as a male or female may not be possible. If the person in need of care is unable to wash, dress or manage basic care requirements then health and social care services will be involved, whether care at home services or care home services.

Many health and social care services are ill-equipped to deal with the needs of transgender seniors, and have had little exposure and so have little understanding of their history or the unique needs of transgender people, who fear that a move to assisted living or receiving care within their own home may leave them vulnerable to discrimination and harassment.

When we think about sexual orientation, gender identity and older people, we overwhelmingly assume that the older people who use our services are heterosexual and non-transgender. As a result, issues of sexual orientation and gender identity have often been invisible in the planning and commissioning of services for older people. The issue is further complicated through a societal culture which seldom seems to recognise or empower older people's sexuality. This is particularly true in instances where the older person is perceived as vulnerable, specifically in a residential or nursing care setting where issues of capacity and consent may make the nurturing of an individual's sexuality more complex. The progressive deterioration of the most recent memory for a transgender person could mean only remembering living in another gender, including not remembering having had gender affirmation procedures or surgery. A real concern of many transgender people is that they will be misgendered in the event that they become reliant on others for care.

One thing, though, is clear – for transgender people, ageing into the later years of life can present a unique set of challenges.

An example of this is older transgender people who were reported to have become distressed within care settings because they

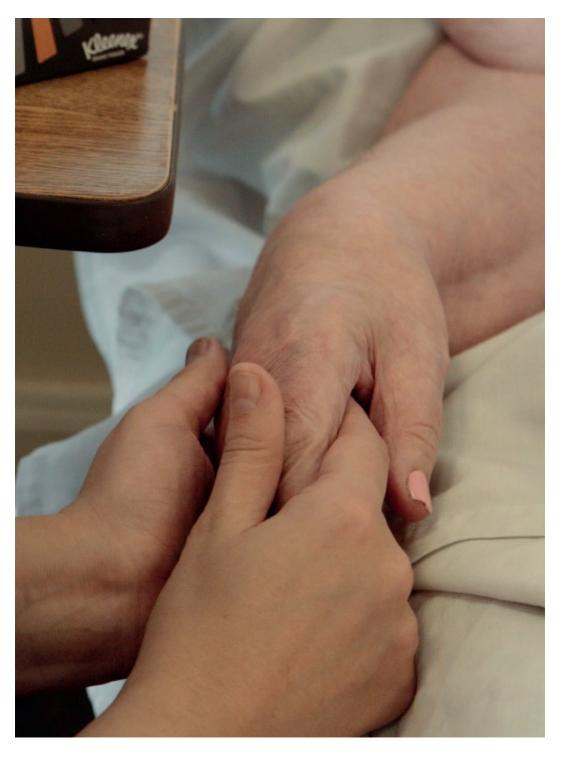
couldn't remember whether or not they have come out to fellow residents or staff and that this was causing significant anxiety to them.

There is limited understanding of how transgender people are affected by dementia. Whilst cultural awareness training for service providers is required to improve the understanding of transgender clients and how appropriate and respectful care can be provided. Service providers also need resources and information to optimise culturally appropriate care for transgender people

There is a long way to go however, we must ensure that transgender people are protected against discrimination, harassment and victimisation on the grounds of gender reassignment.

To this end the Scottish Government has begun engaging with transgender people to advise on trans-specific policies, thus enabling full participation in everyday, and public life by empowering transgender people, changing hearts and minds and creating a network of allies.





### **#voteforcare**

#### Dr Donald Macaskill - CEO

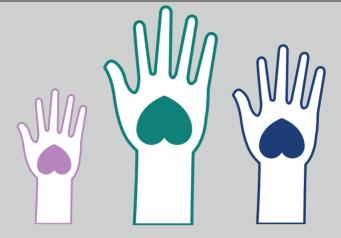
One of Donald's fortnightly blogs, written in the run up to the General Election 2017 but with messages that continue to resonate.

Over the next few weeks if you don't like politics or like Brenda from Bristol you are fatigued by the constancy of being offered to vote in elections and referenda, it might be best if you leave the country for two months.

Within hours of the General Election being announced the political rhetoric was being refined, the battle buses were being serviced and the party spin was being texted to aspirant and existing politicians. Before even 24 hours had passed the print and visual media had polished up their appearance, the studio couches had been vacuumed and the logos and backdrops had been redesigned.

There is on one level something theatrical about the 'event' which is an election, whether at local or national level. The machine whether smooth or juddery, new or old, usually follows predictable tramlines. We've already had a dose of mud-slinging mixed with accusations of betrayal and personal condemnation. Increasingly you either love it or loathe it.

What is inescapable, is that all too often the critical issues get brushed aside by a wave of reportage which focuses on personality and a popularity contest. What is regrettably all too common is that debate and rhetoric are reduced to sound-bites rather than an articulation of complexity and a search for shared solutions. What is almost inevitable is that an election diminishes consensus and consolidates polarity.



The role of an organisation like Scottish Care is always a challenging one during an election. We walk a tightrope seeking to avoid being party political whilst at the same time wanting to articulate the issues that matter to our members, to workers and the people being supported and cared for.

Social care has rarely been at the critical juncture it finds itself at the current time. We are a sector no longer on the edge of crisis but daily battling for survival. That may sound melodramatic but it is the acute reality for all too many.

So, we aren't going to tell you who to vote for but over the next eight weeks through the Scottish Local Elections and up to the General Election what we invite you to do is to #VoteforCare. We will release weekly statements on what a Vote for Care might mean.

We invite you to ask your candidates and parties, what are they planning to do for social care in Scotland?

## What will they do to address the fact that:

- We have a 28% vacancy level for nurses in care homes in Scotland
- We have 9 out of 10 home care companies struggling to recruit staff
- We pay as a society only £3.97 per hour to support an older person in a care home with 24/7 intensive nursing care
- We pay our frontline care workers on average a £1 less than they can get for stacking shelves in the local supermarket
- We have workers forced to get someone out of bed, washed and fed in less than 20 minutes
- We have people being cared for in their last few days by staff who are stressed and burnt out because of overwork
- We have family carers at breaking point because more and more is expected of them
- We risk losing 1 in 12 carers who work in Scotland but come from Europe
- We daily hear from older Scots who feel they have been shortchanged in the care the Government will pay for them
- So whoever you are, someone who receives support at home or is cared for in a nursing home, a family member or a friend, a care worker or someone who simply wants the vulnerable to be supported with dignity, let us all make care matter in the midst of the political noise.

Let all of us ask candidates what they plan to do, not just what they plan to say, and together let's make sure we all #VoteforCare.



### **Kick the Sides Off the Box!**

Julie Fraser - Care at Home Development Officer, North & West Highland



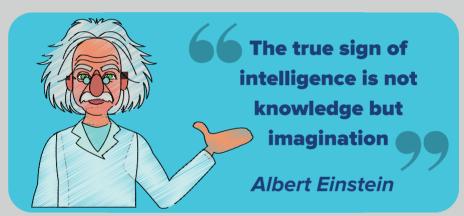
I think when I came into this world; one of the first words out of my mouth was "why?" Quickly followed by "how, what, when, where, and again why". You can feel for my poor mother! I questioned everything about the world... why are things done that way, how does that work, what is the point in doing that, who benefits from doing things this way...and most importantly why do we give our compliance without questioning any of it?

And well, a few decades down the line, that hasn't changed much... I still "won't tow the line" as my mother delicately describes me to others!

Over a year into this Scottish Care Development Officer role and I have found the perfect fit for my ever-questioning mind. North and West Highland covers a huge geographical area (if I remember correctly Highland area covers around a third of the whole of Scotland).

However, this offers unique challenges in terms of devising and developing care services over such vast and mainly rural terrain.

A high reliance on traditional NHS care at home delivery and a lack of any available service in some areas, the scale of the challenge is great. But the timing of this drive to improve and increase care services could not have been better. With a focus on community empowerment, with Self Directed Support legislation changing the way we think about delivering services and with an increasing ageing population and a government focus on the care of the future - we are in an environment of possibility. A blank canvas if you like- with the paint, paint brushes and subject all waiting to create "a masterpiece"!



So we can kick the sides off the box. More and more there is a drive towards new innovative services, new models of delivery, moving away from "what we have always had". As said above, let's not think outside the box, let's kick the sides of the box away and think like there never was a box!

Let's not work from what we have, but work from what we need and how we build it. When a service user recently told me she could not plan a holiday like any other person would plan a holiday, I asked her why not?

And yes she has a disability, and yes she has a motorised wheel chair, and yes she needs support to eat, drink, move, all of those things. And yes the team around her want to keep her safe and secure and for no harm to come to her.... But she has always wanted to visit Rome. So we are working through all the reasons why it might not be possible, and are finding ways to make it possible - because that is what is important to her. Making the same choices anyone else would make, and weighing up the options and putting in place the supports that are needed to achieve that.

We have to break down that box where we put people for our own peace of mind! Our thinking should focus on what is possible, regardless of what has come before and what hurdles might be there in our road. Anything is possible!

In Highland we have taken this opportunity to rethink things and have run with it. We have some very innovative stuff happening and this seems to be contagious and is growing. Communities are becoming more empowered, and as the pioneering examples show fruition, others build in confidence to embrace the opportunities that our forward thinking commissioners have offered

We are exploring a large variety of new and different ways of delivering care. When you live in a rural and remote area, you are forced to think outside the box, as the box was designed by someone in a city and it never really fitted anyway!

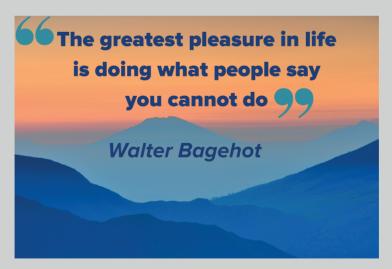
In Highland we have care homes adding variations to their businesses by expanding into care at home delivery, day care centres looking to develop into care at home, small micro enterprises working within their own local communities across Highland, co-productive, collaborative relationships with

the NHS, an overnight service that operates between 3 local providers and we are exploring how to develop 24 hour services in rural and remote areas – perhaps a joint venture between care at home providers and an emergency service.

# Anything really is possible when you kick the sides off the box!

Another element of the current climate that I am passionate about is Person Centred Service Delivery. Coming from a background of person centred counselling at a time when nothing was considered more dangerous than to let people make their own decisions- it is mildly odd but thoroughly refreshing to now be in a world where we are strive to develop person centred services. Understanding the term and the basis from which it comes, rather than just using the latest "buzz" word, is our next and biggest challenge.

When we achieve that, we truly will have kicked the sides right off the box!



# End of life care does not stop when the heart stops beating

#### Alison McPherson - Care Home Manager, Hillview Care Home

As a home manager, the care home I manage provides care for 57 people; 28 people who are living with dementia, and 29 younger people who are living with alcohol related brain damage.

Some of the residents do not have family members, through estrangement or because they have outlived their relatives and for these residents, relationships with the staff members are the closest to family that they have.

When a resident died, he was a few hundred pounds short of paying his funeral. As there was no family, there was no one to claim benefit or contribute to the cost and he ended up in a pauper's grave with no marking to remind people of his life.

This was distressing for the care team. We discussed this within the team and it was decided that the care home should purchase a plot in the local graveyard where we could respectfully lay our residents to rest, with dignity.

Since then, the staff have arranged funerals for a number of residents, working with a local humanist (Paul Harkin). The service is planned and the memories of fellow residents and staff members are recorded, and form the basis of the memorial service. Staff members volunteer to be cord bearers for the coffin.

By supporting staff and residents to remember their friend and to participate in the organisation of the service, they are able to grieve. It provides an outlet for their feelings and provides opportunities for other residents to think about their own funeral, how they would like to be laid to rest, what music they would like, etc. For some of them, they had never considered this an option.

Staff members select music to be played, and this is normally songs that held meaning for the resident. For one man it was Status Quo, 'Rocking All Over the World'. For another it was Judy Garland, 'Somewhere Over the Rainbow', as this was from his favourite film.

The memorial service is then held in the care home. The staff members prepare the room and residents are supported to attend. When Paul delivers his service, very often there are not many dry eyes in the room. The hearse is brought to the care home and staff and residents follow to the graveside, where the committal takes place.

On the return to the care home, a purvey is provided and we sit together, as one, to talk about our memories of the person we have lost.

Life has many roads, and for some they get stuck on a path. This doesn't mean that a person should not be afforded dignity at the end of their lives.

## The Dash

Linda Ellis, 1996

I read of a man who stood to speak
at the funeral of a friend
He referred to the date on his tombstone
from the beginning to the end

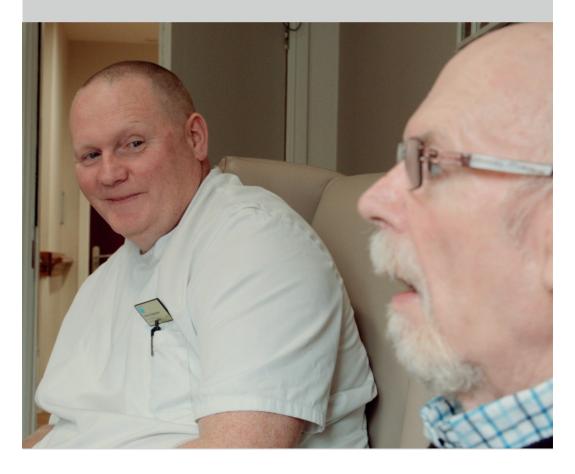
He noted that first came the date of his birth and spoke the following date with tears

But he said what matters most of all was the dash between the years

For the dash represents all the time that he spent alive on earth and only those who loved him know what that little line is worth

For it matters not how much we own the cars, the house, the cash What matters is how we live and love and how we spend our dash.

I'm privileged to spend my dash looking after others, ensuring that every day on earth is a day worth living, is a day where they are afforded dignity and respect. And when their life is coming to the end, they leave knowing that they are safe and that they will not face their final journey alone



### We care because we care

### **Karen Hedge - National Director**

'We care because we care'

When I heard this I sat up, I listened and I remembered. What this lady was telling me was that no matter what challenges she faces, she will turn up, she will be there. But I couldn't help but wonder if, with the need to cover long hours with limited support networks in a socially undervalued sector, there will come a point when she can't care.

I was fortunate to meet this lady, and many other care sector staff, from front line to senior management and executives, when I recently had the honour to accompany Becca Gatherum in facilitating mental health focus groups with a view to exploring both the various mental health pressures experienced by care staff and methods to alleviate these. The resulting report was launched at Scottish Care's Care Home Conference on 17th November.

This lady happened to be a care home manager, but I have since heard the theme repeated by front line staff and by home care and housing support providers.

The whistle-stop tour of people, places, policies and politics that I have been on since starting at Scottish Care in June has also been a whistle stop tour of emotions; echoing the sheer joy, shock, awe, laughter, sadness, satisfaction, confusion, pleasure, frustration, and hope that I (and I wager many others) have experienced throughout a career in the care sector.

But all the while I have been wondering: 'who will care when you can't?'

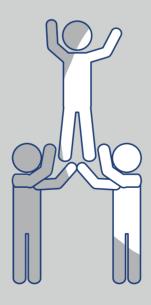
#### Pressures such as:

- A workforce shortage, with 77% of care homes and 89% of home care services having staff vacancies, in a context of increasing need as the population ages and lives for longer with complex needs. The workforce itself is ageing, with 22% of independent sector care home, care at home and housing support staff aged over 55, which puts added pressure on shortages, and of the course the impact of Brexit is already being felt as we lose European workers. And whilst it is becoming increasingly likely that you will hear the phrase 'social care in crisis', sadly the impact that the mainstreaming of this rhetoric may be having is to further compound the situation by making it more difficult to retain and attract staff into a profession which is being negatively portrayed. We need to find and share some positives. I know they exist I am fortunate to have chaired the judging of the National Care Home Awards.
- Providers being unable to invest in staff training and support because they cannot spare them the time off rota, at the same time as knowing that providing that training and support is what is necessary to enable them to continue to care about care.
- The impact of the 'time and task' nature of many commissioning packages which put a time limit on caring. Imagine an actor, had to repeat a 15 min script to a succession of audiences over an 8, 10, sometimes 12 hour shift, then go home leaving the character and any emotional connections behind. But these are not actors playing a part, they are real people forming real caring bonds and connections. As a former commissioner I remind my colleagues that the fourth part of the commissioning cycle is review, and that is not just a review of the provision, but also of the commissioning itself.

And whilst there are many more pressures I could go on to list, this activity in itself does not answer my question, but it does help me to see my role at Scottish Care more clearly.

As a membership body, we have responsibilities to our members, but we also have unique access to a wealth of knowledge and information about the sector which we can promote and use to provide the evidence for change.

So, instead of asking 'who will care when you can't?' I will now be asking, 'what can I do to support you to keep caring?'.





#### With Thanks

Scottish Care wishes to thank everyone who has contributed to our blog series throughout 2017. Every single one, whether written by a member of the Scottish Care team, a member, or one of our many valued partners, has provided a different perspective on a range of issues and experiences.

If you are interested in contributing a blog piece in 2018, please contact kat.macmillan@scottishcare.org

Photo Credits: Mike Rea

