

“This
Speaks
to
Me”

PART OF THE CARE CAMEO SERIES



Preface

Over the last year Scottish Care staff have heard amazing stories of care beyond dedication from homecare and care home staff giving solace to those living with terminal illness and at the end of their lives.

'This Speaks To Me' is part of a palliative care project called 'Supporting Solace' which is an attempt to highlight the care and support given by thousands of care staff. It grew out of a realisation that for many people it is in the forms of poetry, image and prose that they have found vehicles to speak truth, to share emotions and feelings which are often hard to articulate.

When your own or the life of someone you love or care for is coming to an end, whether imminently or over a long period, it is often hard to find words which speak to the vast contradiction of emotions that are felt. At such times people are looking for honest and authentic communication rather than pious platitudes.

In reading the contributions in this Scottish Care's latest Care Cameo I think you will agree with me that it contains words which paint truths which are raw and real, beautiful and breathtaking, humorous and human. Part of that truth is that we all need to find support and solace at times of questioning and confusion, in the midst of hurt and anger, and when feeling confused or desolate. At such times for many folk simply being still, reading a poem, looking at a picture can overwhelm and console in a way that a simple conversation might not.

This work is dedicated to all those who read this booklet at a time when they or others they love may need solace and support in the hope that you may find it here.

Dr Donald Macaskill
CEO Scottish Care

“ My husband passed away just over 2 years ago, after being diagnosed with cancer and taken from us within 5 weeks of diagnosis. It was a horrendous experience for him but also for myself and our children.

What I would like to say to anyone supporting a person through their palliative care is always to remember to include the family as much as possible as they will be struggling too and this will be their last memories of their loved one.

Encourage people to talk about
happy memories
with the person and their family.
Smile, laugh
with them and just be there to listen.

”

Anne-Marie Liddell

Care Services Manager, Blackwood Group



Beyond Words

Illustration by Karin Georgiana Eremia

“

Good palliative care is built on good relationships. With a gentle approach, people with dementia continue to connect in lots of ways - a squeeze of the hand, a wink, a smile, a hug, a kiss on the cheek. Even in the advanced stages, people with dementia are still fully present and open to connecting - when we have the courage to be present - beyond words.

”

Dr Julie Watson
University of Edinburgh

Always There

When you remember me,
Please do not weep.
My body may not be there.
It has chosen to sleep.
I'm not that far away.
My soul lives on,
Looking down, watching over
You and everyone.
And when you feel sad
And life seems so blue,
Just remember
That my spirit has its arms around you.
And on those special days,
Times that you wish I could see,
That cool breeze flowing past you...
Well, that will be me,
So don't be sad.
Have no fear.
God has taken me under his wing,
But I'll always be near.
I still watch you
Every minute, every day.
My love and soul are with you,
And that's where they will stay.

Emma Marie Etwell

Submitted by Tailor Maid Healthcare



The Other Side of Memory

I close my eyes and remember...

all those days that we have shared;
when you brought a bright spark
to cold and damp monotony;
when we collapsed in side-splitting laughter
about the nothing things of life;
when we listened to a piece of music
and tears sounded to its rhythm.

I close my eyes and remember...

all those faces that we have watched;
the fearful thrill of cradling life
as young new-born parents;
the certainty of adult doubt
as teenagers looked for answers;
the aching loss as the bone of our beginning
shrouded itself into the earth.

I close my eyes and remember...

all those places we have wandered;
the homes that we have furnished
with the love of our welcoming;
the journeys we have made
whose destination was beyond a horizon;
the hearts and lives we have changed
though we were blind to the knowing.

I close my eyes and remember...

all those graces we have been given;
the gentle glimpse of your hand,
open to share and bring comfort;
the smile which put at ease the stranger
and made them a friend for life;
the timbre of your content
as music filled a room;
the fragility of your strength,
from knowing love in our midst.

I open my eyes and recognise...

that as the sun sets on this day,
as dusk scatters light
into the encroaching dark;
so somewhere,
on the other side of memory,
you are there.

And in that place beyond all sense
the sun is already shining,
the light is growing,
as the dawn of new beginning
aches its way through love's pain
and loss's mourning.

I open my eyes and see
that you and I are
both here and there,
both memory and future;
a life lived,
a love shared,
a beginning started,

A light rising,
over there
on the other side of memory.

Callum Campbell
Long term care home resident

Edith's Journey

Edith awoke her mind filled with fear, admission to the
care home was growing so near.

No family left, unable to cope so the decision was
made and she was afraid and bereft of hope.

The first day in care and a nurse entered her room,
With tea tray in hand and said 'all will be grand',
Edith retorted: 'How can that be? I have no family left,
no one to care! When my end comes will someone be
there?'

'Edith you are not here to die you are here to live', was
the nurses reply,

'Once you are settled you will soon see, how good for
you this home will be'.

'Outings, events and barbeques in the sun with care
carried out second to none, you will see'.

Edith did settle and was happy and contented, happy
to be with her new family the staff who she had
adopted.

Edith spoke to the nurse of what she expected, in the
event of her death Edith made her wishes very clear:

'It is my intention die here at home',

'Free from pain and please not alone',

'My funeral was paid for years ago, look in the brown
box it tells you what you need to know',

'Spiritual comfort to be given near the end, with
wedding band on finger and rosary beads in hands',

'Blue suit in wardrobe is what I will use, and please
make sure I have on matching shoes'.
'I would like my hair to be done up in a bun and then I
am sure all will be done'.
Nurse wrote up Edith's End of Life Plan and gave it to
Edith for her to sign,
Edith did this yearly until her decline.

They were together in the stillness of the night.
Edith wakes up and says, 'Am I alone?' and holds up
her hand.
Nurse clasped the hand tenderly and said, 'Edith I am
here'.
In Edith's eyes there was no fear.
Nurse was holding back her tears.
Edith went gently, a death free from pain,
In death as in life she held the control
And a good death for her is what she did know.

Cooriedoon Care Home

Contributed by members of staff



A Red, Red Rose

O my Luve's like a red, red rose,
That's newly sprung in June:
O my Luve's like the melodie,
That's sweetly play'd in tune.

As fair art thou, my bonie lass,
So deep in luve am I;
And I will luve thee still, my dear,
Till a' the seas gang dry.

Till a' the seas gang dry, my dear,
And the rocks melt wi' the sun;
And I will luve thee still, my dear,
While the sands o' life shall run.

And fare-thee-weel, my only Luve!
And fare-thee-weel, a while!
And I will come again, my Luve,
Tho' 'twere ten thousand mile!

Robert Burns

Scotland's National Bard

1759 - 1796

Poem submitted by Marjory Barton,
Beechwood Care Home

Annie

I see tiredness and fear,
as I look into your eyes,
So I take your shaking hand,
and place it straight into mine.
Every time we speak,
you say I make your day,
I was so shy at first,
I didn't know what to say.
My words were slow and jumbled,
What did you want to hear?
You liked hearing about my friends it seemed,
and what I'd learnt this year.
I liked washing your hair,
As you'd hum with happiness,
Because we laughed about my weekend,
And all my clumsiness!
The professional code states,
That we're not meant to be friends,
But I've looked after you for weeks,
and now we've reached the end.
Your family couldn't make it in time,
They live too far away,
So it's just you and I sitting here,
It's a bright and sunny day.

You say something so quietly,
So I listen for the words,
They're the last thing that you spoke,
So I make sure that they're heard.
I didn't get to meet you,
When your body was on your side,
The view of patients lives,
That nurses often get denied.
You told me stories of the younger you,
And the family that you'd raised,
As I did things you once did for yourself,
You pretended you weren't fazed.
You were the first one to leave me,
The first hand I held to the end,
And despite my student nurse badge,
I thought of you as a friend.
I've sat with many others now,
Given them comfort by being there,
But the room still goes cold each time,
As if it's suddenly all bare.
Every time I wipe the tears away,
That have fallen without consent,
And I remember why I chose this path,
And what being your nurse meant.

Ellie Jolly

Third year Adult Nursing student,
University of Edinburgh

Listen to Me

If I am unable to speak
I can still hear you,
Talk to me I'm still here
We all live and we all die

Please make my journey run smoothly
Let me be surrounded by people who care,
If this is the last thing you do for me
Let both my journey and end
Be filled with dignity, respect and be pain
free

When you go home you can say to yourself
Jessie lived and died well
And take pride in the part you played
As a caring and compassionate human
being
You never know when it may be your turn
Ask yourself, what would you want?

Breedge Reid

Care Coordinator, Primecare Health



Such a Simple Thing

"Do you mind if I talk to you, lass?" Faither asked me one night, as we watched the television together. "I want to know if you'll help me. I need to know if I can count on you."

I speechlessly nodded my assent. He had oesophageal cancer, and he had been staying with us – his younger son and me, his daughter-in-law, for the last few months, so that we could support both him and his wife. Now, as he embarked on his last few weeks of life, he wanted to explain simply what mattered to him.

Quietly and deliberately, he began:

"I have three requests."

I waited expectantly.

"Firstly, I want to die here, in your home, with you looking after me."

I nodded at this. It caused no problem, and I was pleased that my care was of value to him.

"Secondly, I do not want to go into hospital again: I know that they have done their best, but I want no further treatment."

Again, I understood - everything that could have been tried was tried. He was now tired of it all.

"I shall certainly make your wishes known, and advocate on your behalf." I responded. "But are you saying that you do not want any treatment, whatever the cause?"

"That is correct," he answered, clearly. "I'm satisfied that everything that can be done has been done. I want to be able to choose my end." I said that I would attempt to meet his specifications, but that I could not guarantee it.

He took a deep breath before continuing with his last request.

"Thirdly, and more important than anything, I want you to call Time. Can you do that for me? I know I am asking a lot."

I swallowed hard. Thoughts raced through my mind. What could I say to this man who meant so much to me?

"When the time comes, you may not be lucid enough to express these wishes? Is that what you mean?" I fudged.

He nodded.

"I trust you, lass," he responded. "If I am unable to say 'I've had enough!' will you say it for me?" he appealed.

"That's a whole bundle of trust. Are you sure?" I asked, now overwhelmed by the burden of responsibility.

"I couldn't be more positive. I've watched you caring for others. You won't get it wrong. I will be much more confident that I'll not be required to suffer any humiliation or distress if you agree."

"So you are asking me to call Time?"

He insisted that this was his wish.

I was honoured, yet terrified that on this I would fail.

I did not see how it would be possible. I expressed these reservations to him.

"Can we call it something, then?" he asked.

"What did you have in mind?"

"I would like to call it 'Dying with Dignity'."

Linda Jane McLean

Social Care Researcher

An excerpt from 'Such a Simple Thing'

https://drive.google.com/file/d/0BxCdr0U_0m7ycDdTYi1kaDIWSIk/view



It Cannot

Death
does not hold me
though it touches
as I pass by.

It cannot deafen
your whisper of love
though it sometimes
fills the sky.

It cannot blind me
to the lights of hope
though its darkness
can make me but for
a moment grope.

It cannot freeze my feeling
or cool your spirit's warmth
for its heat is transitory,
its pain a passing sore.

It cannot drain my soul
of all the memories of
smile and tear
though it clamours to
empty my living.

Death,
truly you are
a mask
and I can
and do
deny your power.

Callum Campbell
Long term care home resident

With Thanks

Scottish Care wish to extend a sincere and heartfelt thank you to all those who have contributed to the This Speaks to Me project. It is your willingness to share so many personal, moving and insightful items that have enriched the pages of this resource.

This Speaks to Me contributors:

Marjory Barton, Beechwood Care Home

Callum Campbell, Long term care home resident

Karin Georgiana Eremia, illustrator

Emma Marie Etwell, poet

Ellie Jolly, University of Edinburgh

Anne-Marie Liddell, Blackwood Group

Linda Jane McLean, Social Care Researcher

Breedge Reid, Primecare Health

Tailor Maid Healthcare

Gwen Walker, Cooriedoon Care Home

Dr Julie Watson, University of Edinburgh

About the project:

This Speaks to Me was conceived as part of Scottish Care's Supporting Solace project, which has seen research with front line support workers within our member organisations exploring their experiences of palliative and end of life care (PEOLC).

The aims of the various strands of the Supporting Solace project are as follows:

- To gain an understanding of the level and range of PEOLC support being delivered throughout the independent care sector, and any challenges associated with this delivery
- To identify the current skills, plus the training needs, of the front line care workforce in the independent sector
- To explore the emotional, psychological and spiritual impact on front line staff of delivering PEOLC
- To identify any recommendations which would better support PEOLC delivery within an integrated workforce environment
- To identify innovative and best practice around PEOLC provision within the independent sector

We had a tremendous amount of interest in this research from organisations and individuals, demonstrating both the relevance and importance of hearing the experiences and ideas of the expert workforce at the front line of social care in Scotland.



Scottish Care
Voice of the independent care sector



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