

Carers' Words, Carers' Lives



Writing by carers with Care for the Carers

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Carers' Words, Carers' Lives is an anthology of writing by carers with Care for the Carers working with writer in residence Evlynn Sharp.

Care for the Carers is a charity for unpaid carers in East Sussex. Do you look after someone who couldn't manage without your help? We're here if you need information, advice or support.

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“Each day has to be taken as it comes...” – *Tash*

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*Carers' Words, Carers' Lives –
Writing by carers with Care for the Carers*

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Introduction by Jennifer Twist

This anthology contains poems by carers who have worked with the Care for the Carers team and our writer in residence, Elynn Sharp, to write about their personal experiences – on themes from isolation to courage. Most of the work featured in *Carers' Words, Carers' Lives* was produced during creative writing sessions with young adult carers and in writing workshops as part of our Carers' Toolkit courses. Another contribution to this book comes from carers attending a creative reflection session held during their regular monthly meeting group, where carers connect with one another, discuss aspects of everyday life and caring for a loved one.

We all have a unique story to tell that reveals the journey our lives take us on. It can be empowering and freeing to share who we are, our recollections, our wisdom, our sense of place, people, days and years, our hopes and beliefs, our pain and our joys. The aim of Care for the Carers' Writer in Residence project is to recognise the significance of caring for others, and bring together carers of all ages and walks of life to craft and share their stories in a safe and creative space.

When so much in our environment can put pressure on us, it can be a comfort and a relief to simply take time out for creative writing, for finding ways to express our feelings and beliefs, for talking about our views so that others might hear and be with us in empathy and compassion. We hold sure certainties in our words, the strong freedom of our voices within, and at the heart of creative writing practice is a willingness to deeply listen to ourselves and to others. *Carers' Words, Carers' Lives* presents a unique glimpse into our lives and is a rich legacy of what matters to East Sussex carers in the here and now.

Jennifer Twist
Chief Executive Officer
Care for the Carers
May 2017

FROM INSIDE

Denise

Behind my mask is a woman
Who was once a wife,
A lover,
And a partner,

But who now wanders aimlessly
Across the room –
No conversation,
Nothing to really look forward to –

The holidays and days out,
Just a distant memory –
Where is this all going?

My life was once so full –
The laughter now so seldom shared,
The fun and cuddles
That made a moment special,
Just a faded memory.

How have I arrived at this place?
Just washing,
Caring,
And bandaging –

When will I see another side –
Why do I get so sad?

He is still my man really –
He's just gone from inside.

BRAVE FACE

Smash (S)

Behind my mask is...
A sad and unhappy person.

I put on a brave face
So people don't think I'm weak

And that I can deal with
What life throws at me.

Sometimes
I hate feeling these things,

But it comes with the loss
And sorrow

I have had to deal with
In my life.

ALONE

Emma-Louise (C)

Behind her mask
Is a fragile,
Unconfident girl

Who is scared
Of being hurt
And left alone.

I HAVE COME THROUGH

Diane

If you looked into my eyes
You would see...a caring hopeful person
Not always sure of which way to turn.

Lately I tend to overthink various situations
And this may be due to advancing age;
I don't remember being so concerned about such things
When younger, i.e., being on time for appointments,
Stressing about minor things.

I have come through a less than amicable divorce
And am told that it took "years off me"
So I am grateful for that.

There again, the conditioning kicks in
To think of the positives
And realise I am very lucky
Compared to so many people with problems;

Just be grateful for health and family,
Don't regret what you can't change
Especially past mistakes.

IF YOU WERE TO LOOK INTO MY EYES...

Mary

You'd see a woman who is still struggling
To decide what to do with my life,
And what I really WANT to do – and who I am?
But my life is circumscribed
By other people's needs.

You'd see a woman who wanted to be Mary,
But spent her life being Martha.
Who wants to be creative,
But spends her life dotting the i's and
Crossing the t's for other people's creativity.

Who has spent more time helping others
To play the music I love,
And not enough time myself
Playing the music I love.

Who is a pessimist – seeing the glass half empty
Rather than the glass half full!
Who must remember to count her blessings,
And take pride in her achievements – however small...

Who now has a specific task to do,
Not of her own choosing.

Who is overwhelmed by a sense of duty
Rather than freedom of choice.

Constrained by being a perfectionist,
By lack of confidence, and many regrets.

TRUST / NO TRUST

Anon (C)

Behind her mask is someone
Who is crying inside,
But on the outside
She's always happy.

Her life was great,
She was happy inside and out
And spoke to anyone
She trusted.

But as she got older,
Her trust with people was lost,
And now she hides it
Behind a mask.

FORGET IT

Jordan

I just want to forget
And not write about it
As it's just too hard.

THE TRUEST NAME

Kate

Call me by my true name. 'Well trained,'
Said Jane, the wife of my mother's friend,
As she watched me
Providing every comfort to her.

The moving and handling from wheelchair
To perfectly-placed armchair;
I make it look so easy.

The cushions of comfort behind her back,
Table, arm positioned just nicely,
As with the feet.

Coffee made exactly right,
The whole room designed
With her preferences in mind.

Do I want to do it?
Actually I don't know, I can't truly say.
I just feel I have to because
I cannot face the alternative,

The casual careless unthinking thuggery
Of the care home.
They would not respect your art materials,
Or your need to use the loo instantly
The moment you mention it.

It is your nightmare and mine also.
I would rather die than be confined
In such a stifling space.

And so I stay with the familiar,
A form of disagreeable compassion,
Because I choose resentment over guilt.
Well trained.

BEGINNINGS

Rita

I have a vision of a rather desolate place called Seasalter.
I had my first real holiday there –
With an aunt and a couple of uncles –
As a 13-year-old.

We stayed in a little shack on the beach
With a pub nearby.

The beach was stony and the area was bleak
In the early evening sun.
Auntie and I walked along the sea wall –

Miles and miles it seems. I felt happy and secure
Because she and I were walking
Hand in hand.

That was 65 years ago.
We reach our destination –
Fish and chips near the Blue Anchor in Whitstable.
Silence filled the air; I wondered,
How on earth could we spend a week here?

Yet it was the happiest holiday I ever had.
We made our own entertainment.
Outings, cards, darts; unlike today.
I long for the companionship
I had on that holiday.

Beginning to feel grown up.
Now I am very grown up.
I long to be that child again.
That child is still within me.
I haven't changed.
Yet all around me is change,
Responsibility, a carer;
Bills, shopping, housekeeping.

One thread along the years has been my faith –
Faith in a God who created everything.

BETWEEN ONE MOMENT AND ANOTHER (extract)

Meena

My partner and I love to travel
And visit places around the world.
As a carer for him and also out in the community,
It is *always* a struggle to balance my time
And our limited funds
To achieve our favourite pastime.

When he first told me of his MS,
I promised him I would do all I could
To help him along the difficult path ahead.

We would build as much humour and silliness into our lives,
And take every opportunity
To make at least little steps of change
To accommodate this terribly debilitating illness.

Our lives – and I say *OUR LIVES* – have changed so much
Since we first got together.
Him as the sufferer; me as his carer.

The compromises, the disagreements,
The hurt feelings – back and forth,
Back and forth, round and round,
And ending up in a huge hurt bag.

It has been so very difficult to help him
And live this MS path.

To find the support has not been easy
So we quite often make it up as we go along,
Even joining a dementia group
So that we have a bit of crazy, confused, bizarreness
To take our minds off our everyday struggles
That his health throws up...

THESE LIVES, THESE TIMES – group poem

By Chris, Peter, David, David I, Diane, Colin, Doreen, Meena, Heather
With Mark Tolhurst of Care for the Carers

This is my life. At the moment, I don't know
Where I'm going, I was letting myself go
Further down. The courage is in getting out
Sometimes; I'm doing all the family chores;
I'm doing the shopping for the family;
I'm the sole carer for my son who has autism,
He'll be 21 next year; he's a bit like a 4-year-old.

This morning, this is my life –
I haven't the confidence
To go out and do anything;
It's hard when you're the only one,
And people live away.
I want the courage to go ahead,
I'm thinking of respite care for my mother.
My courage is in making that decision
About respite care for my husband;

But it's not easy,
I want to get rid of the guilt feeling;
It's not been easy – the guilt and tears –
I have to get rid of the guilt...

We were conditioned as children –
The parents looked after us...now,
This is my life. I am an only child,
I care for my mother who is 95;
I live nearby; I'm fortunate;
I'm finding it a bit of a strain –
The same questions time and again.
I have sons but they live way;
I try to do things for my mother;
Time and again, the same questions;

My life is I care for my mother who's 80,
The last eight years...declining in health.
She had a nasty fall; the onset of dementia.
I go in four times a day. It's not been easy.
She was becoming so dependent on me.
Phone calls at all times of the day and night;
I was becoming unwell.
She won't get better just gradually worse;

The age I am, I have to think of my well-being;
I've come to the conclusion...I need help.
And this is my life. Most of the time,
My wife and I are blessed with how we're coping.
She has the brains, I'm the brawn.
My wife and I look at how blessed we've been...
Sometimes, we feel a little less than blessed;
My son died with MS; my wife has MS;
We soldier along...

And this is my life – married 56 years,
I care for my wife, I look after my wife,
She has multiple things wrong,
She is so unsteady;
I can't pick her up on my own;
She's not demanding;
She can't feed herself;
I do the cooking; I'm happy in my own way.

And my life is my parents disowned me,
They didn't come to my wedding.
I have this lovely wife who stood by me,
And I had lovely in-laws, who passed on;
My wife has Parkinson's, a stroke, MS,
And something else; it pulls you down a bit.

My wife talks at night.

I wanted to move years ago, she wouldn't;
In the place around me, I have to be careful,
There are blue lights flashing around me;
No quiet time at night, there are druggies,
Drunks – no quiet time around me.
Pulls you down.

I'm 78 now, retired now, I had a stroke 15
years ago, I suffer from asthma, stress, panic;
I'm not getting answers about my wife's health.
I look at forms, my brain doesn't absorb them;
When I think about forms, I shake and sweat...
I used to be able to help people,
All that confidence has gone;

I wanted to give something back,
Not just take. I like following ships
Up and down the channel.
My wife likes her knitting.
She's a smashing wife.
She talks at night.

You get to the point where you think,
'Am I in the way?'
I have been to that point.
A thread runs through,
'I want to do the right thing.'

I have a faith. I talk to carers.
They find out answers.
If Care for the Carers would ever disappear,
I would be in a mess.
A thread runs through,
'Look after yourself.'

Look after myself?

I don't know what to do.
I feel I am in a prison sometimes,
I have a husband who has dementia,
And I have visual impairment.

We've been married 66 years.
And it's the constant questions,
I had 40 questions exactly the same,
All the time...all the time,
I am in a prison sometimes;

And this is my life. Married 56 years.
Twelve years ago my wife had a blood clot.
The first eight years were not too bad.
Now she is worse and worse,
She has the shakes. At the end of the day,
It feels like we're not doing enough,
But we can't do any more.

It doesn't help to feel that you're inadequate.
You think, 'I can do this.'
You think, 'Can I do it tomorrow?'

This morning, the bed was covered in blood.
So it's washing on the line.
I've done the housework.
But when you stop, you start thinking,
And in the back of my mind,
You don't want to lose them.
But you know you are going to have to...
Feel guilty. Can't do more.

Last summer, I couldn't cope any more.
I came to Care for the Carers.
My partner has MS...
Challenging, abusive behaviour...
We needed help.

And I've had to care for my mother.
I thought I would be able to cope,
I consider myself a strong person.
And the caring role, it's my own profession.

Stupid me. On the other side of the fence,
It's different, difficult,
When that person is living with you 24/7.
I have to put on a smile
Every time there's a dip in his mood,
I have to be bright and happy;
It is hard to keep going,
And keep going for another person
At the same time;

I still have to deal with my mother's problems,
But I can't concentrate on her problems;
She calls in the evening, even if I'm in bed;
She's very negative. My daughter stepped in;

My daughter is still in her twenties;
She'll help me. I feel so guilty.
I think I'm burdening my daughter.
On the other side of the fence, it is different.
And it is difficult. I have to put on a smile.
But I'm anxious, I'm everything I don't want to be.
And I am split. There is not time for me.

WHAT I REMEMBER

Alannah

When I think about my life,
I remember wishing
That I could take away the pain
And make it go away.

I remember our holiday,
Everything seemed so normal,
Walking around the park.

Now I see you
In too much pain to move,
And I wish I could take it away.

I remember growing up,
Saying to my friends
I could not come out. But

Truthfully, I said it
Just to stay with you.
I wouldn't have it any other way
Because I love you.

FOREVER WAITING

Sophie

When I think about my life...
I see a lot of pain and heartache.
I'm waiting for the pain to go away,
I struggle so much with coming to terms
With the situation. I think,
Am I enough for him now she ain't here?
I hope things will get easier. But I also think
This pain is gonna be here,
Forever.

WHAT I SEE

Chantelle

When I think about my life, I see pain, suffering.
I feel helpless, I can't do anything.
I watch things go downhill,
I see people fall
And watch them get back up
But not you. I want to help
But there is nothing I can do.
When we talk, I feel I'm losing
Another part of you.
There is so much I want to do,
And say, but I can't.

NINE YEARS

Chris

My life as a whole has been b*****
Because for nine years I have been non-stop bullied
And incapable of knowing my own strength.

IN MY LIFE

Sammie

When I look back on my life,
I see a lot of discomfort and heartache.
I see struggle, and a lot of time waiting
For good things to happen.
I see a lot of talking to strangers
About my problems – as if it is going
To make things better.

MOST PRECIOUS, MOST COURAGE

Group poem by Young Adult Carers

With Rachel Hesterbanks, Care for the Carers

My brother is precious to me.
My mother is precious to me.
Apart from family and friends,

No one else is precious to me.
So precious in this life is family –
That's already been said – and I know this...

I want courage to tell the truth
About my life from now on.
I want the courage for 'not you',

I want to achieve things I aspire to – promotion!
I want to be confident when I have my operation,
It's scary. I want the courage

To go into college tomorrow.
And, I don't know...precious is nature;
Life in itself is precious to me,

People take it for granted.
And precious to me is my mum –
She is the only one I have left.

My nan means everything to me.
My family is everything to me.
My son is who's precious to me.

WORDS OF WISDOM

Janice

Wisdom comes with age, and with age wisdom.
What does wisdom mean for me, for most of us?
Wisdom is the outcome of the most amazing experience;
Within that experience we struggle to find understanding,
Compassion and love, all human emotions are there
Within this...anger, pain, despair, joy and love.

As a carer, I have experienced every emotion possible.
I did not call myself a carer until my son was sixteen,
He'd been disabled at birth. I didn't want to see his disabilities,
I wanted to trust, love him unconditionally;
This mindset has helped me cope with all the experiences
We have been through together.

My darling son, I could never have imagined your strength,
Your trust; knowing without using words...
People are drawn to you, and you love meeting people,
You have calmness about you even when you are screaming,
It's an understanding. You've always seemed older than your years.
At times you have been my strength, I have been so grateful.

All the anxious times in surgery...but I knew, all would be well.
Something deep inside held me together; inner strength
That binds us all together; survival, love, endurance, devotion.
I think true wisdom is the positive outcome from living life,
Taking chances, being honest, being the best we can be,
Sharing this with the world.

WRONGS

Chris

When I walked through the door,
A lot of weight had been lifted
Off my shoulders;

It felt like I could start anew
Once I moved
To East Sussex.

But it turned out
I was wrong,
It turned out

When I started
At the academy,
For five years straight,

I was non-stop abused
Both physically and verbally –
Unable to escape it...

But now I'm in college,
All the weight has been lifted
Once again.

TIME TO MYSELF

April

I wish I had the courage
To speak up about the things I don't like.
I want the ability to talk about the things that bother me.
I don't like being around people. I want to be able to plan ahead
And have time to myself. I don't want to be afraid
Of bad things happening.

SAY GOODBYE

Anon (S)

When you left without saying goodbye
It was the hardest day of my life,
I couldn't get my head around what was happening,
And I felt I had let you down.

I knew I would never see you again,
I would never feel your touch or hear your cry,
I would never kiss your bruises better
Or cuddle you when you're sad.

I would never watch you grow
And achieve great things.
Life will never be the same.

SAFE

Tash

When I walked through the door,
The heat of the safe house hit me.
I was home! Back to my safe place
I call home. Back with the person
I care most about. The love filled my heart
As I walked through the safe door.

GOODBYE TO HER

Tim

When I left
Without saying goodbye
To my nan,

How I felt...
I was so sad
And on my own.

I did not say goodbye to her.
I really wanted to say goodbye,

But I was at my nan's home,
And when the family said to me
She passed away...

I feel so destroyed inside.

I want to go to the hospital,
But I could not.

When the days and weeks go by,

It was getting to me.
I did not know what to do.

After one week,
I had to go and see her.

And I want to,
And I did and I did not
Want to...

LOST SO MANY

Jordan (D)

My life has been absolutely s***.
I have lost so many people in my life.
The best thing that has happened
Is meeting my best friend,
He has been my rock through everything
And brought me back up from rock bottom.
My nan has been the best part of my life,
She has been there through everything.

HERE IS MY LIFE

Tim

I always help people. I've always been with my mum.
I help my mum be there for me. I have been for her all the time.
When I was a baby, my dad left me, when I was one.
Mum told me when I was 10/ 11. Then when I was 16,
My dad went into hospital, and I did not see him,
And 3/6 months later, he died.
But I've got my mum now. I don't want to lose her.
If I did, I don't know where I will be.
Day to day will be hard for me. But keep on the up.
I always love my mum.

FOR JOHN

Jordan (D)

I'm starting to tear up now,
Thinking about my granddad.

It's hard to write down.
I'm starting to cry.

I don't know if I can talk about it.
I get emotional.

I can't deal with it.
I miss him so much.

He's always on my mind.
He's the one who means so much.

LEAVING

April

When I left without saying goodbye,
I was shocked.
My mum was rushed to the hospital.
She caught pneumonia
And went into ICU.
She was there for a month.
And I only was able to see her...
Three times.
We were told her lungs gave out,
And she could of died.

HISTORY REPEATS

Keely

What I would change...
I wish I had the ability
To speak up about my life,

Tell the truth
About what I see,
Think and feel.

I'd like to be able to change my future
For the better, not only for me
But my children.

I see myself having the same life
As my uncle; I've watched him
Care for my nan

And be alone
Most of his life.
Repeating history.

TAKE THE SADNESS

Tash

The way I see my life is
A life full of mist that won't clear;
I want to take the pain away,
I want to take the sadness away,
But I know I can't.
Each day has to be taken as it comes
Coz you don't know what it can bring.
Planning ahead is hard
But having a goal can help.
Being afraid
Of what the future could hold for you
Is scary.
But take each day as it comes.

LIFE

Jordan

What is life?
Life is a gift –
Because it is;
Appreciate every moment,
Every second,
And live your life
To the max;
All the bad in life –
Can make you strong.

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Carers' Words, Carers' Lives involves the publication of this anthology plus production of a film that features four carers – Cynthia, Josh, Meena and Peter– who share their experiences of being a carer, and four film information posters displayed on Stagecoach buses throughout Hastings. Watch the film online: cftc.org.uk/2017/03/30-carers-words-carers-lives/

Cynthia



Josh



Peter



Meena



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