



The Real Cost of Caring

“A Carer’s Perspective”

Hello,

This booklet has been compiled by a small number of people from within the Community of Gateshead who have responsibility for caring for a relative or friend who has a need of care. It is not meant to be all inclusive and represent 25,000 carers in Gateshead, although it is likely that there will be some affinity realised among most of them.

The word “**carer**” is now a ubiquitous term which represents so many activities and services that it may compromise or confuse the integrity of this creditable duty or degrade the reality of the responsibility.

While ‘Carers’ are steadily achieving recognition among statutory agencies through formal guidance, and good practices, it may sometimes be difficult for professionals and policy makers to recognise the true partnership they must have as, together they mutually attempt to assist, support and sustain people who require care. In so doing they may fail to recognise the reality of need, or the vulnerability and fear the carer may have and that **they** also require support and assistance.

The contents of this booklet are offered by carers by way of explanation of their feelings and the surfeit of emotions that mantles their lives as they care for another person. There is no extravagance here, no self pity or indulgence. Carers are among the least complaining and usually expect very little. On the contrary, this is also a celebration of the pride they feel.

The messages this booklet gives is the “Real Cost of Caring”. It is honourable and seeks only to give explanation and understanding to others so insight and recognition is gained.

We are grateful to the contributors to this book and commend it to you.

Jeff Gray

I feel sad as I look at my sister as she slowly
goes,

I'm really going to miss her.

She really means the world to me,

where nothing else could really be,

As she lies there asleep, inside a dark down
heap.

As I look at her, with a twinkle in my eye,

I say "Please don't go, because I'll cry."

So don't leave me on my own,

As you're the one who brings me home.

Young Carer Age 13

'CARING'

From happy care free day's.
To sudden caring day's
When temper's fail and you can no
longer plan ahead.
When peace prevails "what bliss"
Very short lived we are off again
When people say, just walk away
They just do not understand what they say
You hurt, you cry, you cannot understand why
The pain goes on, it eases
But then it's back again
No rest, no sleep.
We are in a mess.
You love, you care, you soldier on
With careful tenderness.

Jean Spark

"THE MEANING OF LIFE"

David and I married in 1993. It was second time around for both of us. Things didn't start well – in 1994 I was diagnosed with Fibromyalgia and had to retire from work. In 1997 I became an urgent admission to hospital for a pacemaker as a 24 hour tape revealed a heart problem where my heart stopped beating for episodes as long as 17 seconds.

Although I had two wonderful sons from my first marriage David had no children so we decided to try for a baby. It took us 3 years to conceive. David didn't mind whether the baby was a boy or girl as long as it didn't have Down's Syndrome but we decided not to have tests as we couldn't terminate a much longer for baby. After a brilliant pregnancy and labour Roy was born on 24th January 1999. He was 2 hours old when we were given the devastating news and the bottom fell out of our world. By the time he was one day we had also been told Roy had a condition known as 'Imperforate Anus' and required urgent surgery for a colostomy. We weren't certain he would survive the surgery and I wasn't even sure I wanted him to. That day was the worst day of our lives, it should have been the happiest. Depression played too large a part in our lives and a car accident just topped it all off.

Four and a half years and 7 operations for Roy later, until very recently we have often pondered the meaning of Roy.

Continued..

In recent weeks my 18 year old son Richard, who has found the last few years very difficult, has obtained 3 'A' levels and got himself a place a Colchester University in Essex. My other sons, Andrew, has been at Cambridge University for 2 years and it breaks my heart that they've both decided to move so far away even though I'm happy for them and so very, very proud. So now we understand the meaning of Roy, of his life. Roy will probably always be around for us to hug and love. He is a wonderful, beautiful, happy little boy who touches everyone's hearts and he is our reason to live.

As parents you try to always be there for your children, help them achieve the best they can in life and wish them health and happiness. In this respect Roy is no different to his two big brothers and we are certain we will be just as proud of his achievements, maybe even more, what ever the future holds.

Life is very tough for us a lot of the time but this just makes happy times more precious. We must always look for the silver linings. I used to think Roy was the cloud but he's not. He's not even the silver lining. He's the sunshine in our sky and we all love him deeply.

Without my husband and my family life would not be worth living.

Brenda Graham (Roy's Mum)

Only a Carer feels the pain
As each day goes slipping by-
The feeling of frustration-
An anxious wish to just get by.
Overwhelmed by sad and constant stress
From unsupported grief-
Excluded from the joy of life-
Little love to give some light relief.
Frightened when night ushers in the dawn
With long lonely hours to pass-
An unfulfilled life ever so forlorn-
Just a shadow in a looking-glass.
If only someone could understand
How hard it is to cope
Without a friend to listen
And raise a spark of hope.
CROSSROADS: lighten a Carer's heavy load
Help stem the growing anxiety-
Raise stamina a higher mode-
Giving a Carer's life some quality.

AC 8/03

THE UNKNOWN

My mother got sick when I was 8 but
The doctors could not see. That her smiles
turned to tears but never in front of me.

I would hear her weep through my bedroom
wall but never in front of me. I wanted her
pain to go away to see her laugh merrily.
Could it be possible for her pain to
disappear then we could laugh merrily.

But I know that is just a dream as she
continues to cry but never in front of me.

Looking back, now I am 12 and what do I
see that's easy. Mam crying but never in
front of me.

Then Crossroads came to me and what did
I see? That's easy children just like me!

Gavin Howard Age 12

Being a carer is hard because I have to help loads and it is a lot to handle. My brother gets scared when he bleeds so I try to keep him calm by drawing with him or getting his toys and action figures or telling him he is a special person.

He likes it when I go to Crossroads because I always buy him something, I like caring for him but not just him everyone!

It's made me see that there are others out there just like me. Feeling what I feel and probably worrying about the same things. Hospital appointments, bleeds, lumps, bumps.

At Crossroads it's about coming together. Sharing that special bond. CARING
Something that will stay with you forever.

Natasha Taylor-Price Age 10

TOUCHÉ

An invitation to my friend's daughter's wedding arrived several weeks before the Special Day. I accepted with **GREAT** pleasure and told my aged parent (100 yrs PLUS) of the exciting event.

Intoxicated by the idea of 'dressing up' and socializing for a **WHOLE** day away from my caring role, I lost leave of my senses, by not considering the consequences of imparting the knowledge so far in advance.

Thereafter, **EVERY DAY** without fail, the wedding was mentioned and questions asked-

“who will be with me today when you go to the party?”

“I;m sure to be sent a piece of cake”

“Will you wear your pretty dress?”

“You look so elegant.....”

and so on and so on

After weeks of this, like a drip on a stone, I was beginning to wear down and regret my initial rashness.

It was at this point, one particular evening, after another sleepless night, I decided to put a **STOP** to it – no NOT with a pillow!

Continued..

“Mother”, I said “I’m sorry to tell you that the wedding is OFF.”

SILENCE!

PEACE!

A pregnant pause.....then,

“You always say ‘Anything can happen’”

**“Well, what about her wedding outfit?
she’s got that.”**

**“And what about the house they’re
buying?”**

and so on and so on.....

PLEASE no more wedding invitations!

**P.S. Yes I did go to the wedding and had a lovely
time.**

THANKS Crossroads!

MY BROTHER, WILL

Give it to Will, I hear them say
You can have it another day
Oh what the hell
He's not well

Show it to Will, I hear them say
You can see it another day
Oh what the hell
He's not well

Watch it Will, I hear them say
You can play another day
Oh what the hell
He's not well

Crossroads Will, I hear them say
Tasha's going this very day
Oh what the hell
He's not well

Natasha Taylor Price Age10



Where do you start?

How can you explain a lifetime of frustrations, worries, battles fought, hospital appointments, sleepless nights and what ifs, in a few words. You can't.

Andrew as those who have met him will tell you, is a pleasant, happy and loveable young man. He revels in people around him and enjoys their company.

Andrew can't tell us if he has a pain or exactly where it is.

He can't tell us what he can see or how much.

He can't tell us what he would like to eat.

He can't tell us if he is having a bad day.

He can't tell us what he would like to do.

All that takes years of gut feelings and experience.

What is a normal day or a relaxing night. The ability to do what you want when you want. These are luxuries to a carer.

Our one luxury is having Crossroads and a group of carer support workers.

Val, Judith, Cath, Angela and Yvonne with all the back up that requires. With their support and dedication we are given time to relax, have a meal out or see a movie. A well needed break for us.

I can't even tell you what a normal day is because a carer rarely has a normal day.

Rob and Janet Holliday

WHAT DO I KNOW ABOUT CARING?

I have cared for my mother for many years. Caring is having to give up part of your life. It is giving up time with your husband in your own home and not having the holidays which you used to have. Running back and forwards from one house to another, and taking early retirement from your job, that means a reduction in your money. Also having to buy an electric wheelchair for my mother, but it has all been worth it, because my mother was able to get out and have some pleasure and fresh air.

How could you put your mother into a Home when she has been a good mother, bringing you up on very little, when wages were poor sacrificing what ever she had to give to you and to keep you clean and fed on very little in those days, but Mam and Dad managed, and I am grateful to my parents for their love and devotion to their family. Now I am carrying on the caring, and enjoying my time off on a Tuesday thanks to Helm-Care and Crossroads for helping me to be able to do that.

I am also grateful to the nurses for their care and to my husband for his help and support. My only wish is, it would have been nice for my mother to be able to get out to the park, like she used to, and get some fresh air instead of being stuck in a bedroom. It would mean a better quality of life and I would enjoy taking her to the park once more. We would both get more fresh air.

Continued..

Yes with caring you are kept busy – never a dull moment, you do get tired but at least I can get out.

My mother must have a lot of patience lying in that bed day after day and never complaining much – never lost her love for me – so everything I have done has been worth it.

Patricia Smith

What will today bring – smiles, tears, moods or more illness?

More hope or yet more disappointment.

Has the girl I met so many years ago just gone.

And left behind a shell of her former self?

But No

The children we created she nurtures,

The grand-children she loves, our love

Overcomes all stresses.

Strains and financial worries,

And we face each day together.

Joe Taylor

I feel sad about being a young carer.



I feel happy when my Mam plays with me.



I help my Mam by doing the washing up, going messages for her, and by making cups of tea and coffee for her.



I worry about my Mam sometimes.

I get angry sometimes because I do lots of things for my Mam, things like going to the shop for her.



Lauren Duggan Age 9

THOUGHTS OF A CARER

Grieving for the expected, acceptance of reality.
You tell me - I don't know how you cope, I don't know
how you manage!

Deep down my thoughts and feelings – Do I?
I wish I didn't have to – but I do.
I wish things were different – but I have no choice.
So I just need to get on with it – And I do.

The responsibility is -
All consuming, all encompassing, never ending.
Even when apart the responsibility is mine.
Always anxiety and worry -
At school, at work, an evening out, shopping.
Wherever, whenever,
Always waiting for the phone call.

But the rewards -
The love seeking no return, the deep, deep
relationship, the need to be needed.
The happiness when there is a glimmer of progress,

the hope for the future.
The whole life changing experience with it's
immeasurable
rewards.

I feel privileged and blessed to be given this
responsibility – The care for my child.

To hear the words -
“I Love You”
Is all I need to go on.

Judith Thompson

Some times things happen, it makes me sad.
I am sad when my Mam is sad.
My Mam has been in hospital.
She's been very ill.
It was very upsetting.
I couldn't concentrate on my school work.
I cried and cried, but I told my best friend.
She said she was sorry for what happened.
My Dad was very tired so I made a Sunday
dinner for the family.
I came home from school and my Mam was
there.
I was very happy she was better.

Sam Smyth age 12



Having seen a marked decline in my mother's health since I volunteered to look after her.

Although being off work myself through a back injury. I just don't see it as a job or task, it's just doing things for my Mam, that she can't do.

For nearly 2 years I've been caring for her, doing the housework, cooking meals, sorting out bills and forms to fill in, decorating, coping with her needs, shopping, and all the other household chores.

Seeing my mother gradually getting worse can use up a lot of strengths and emotions, ranging from being tired a lot to being anxious and tense which is, probably due to frustration at the decline in her health.

I worry a lot, especially when she has a fall due to her weak legs, and feel guilty and frustrated that I wasn't there to help.

When she is really bad like recently then emotions can run high and being frightened is nothing to be ashamed of.

Although she has had some help recently, I still feel that I have got to be strong and resilient in helping her in every way possible.

Continued...

She is a loving and well loved mother, but seeing her struggle with her problems on good days and bad can leave her stressed and frustrated at being the independent woman she is or was, or would like to remain in any possible way.

She doesn't get out much due possibly to her lack of motivation which for all my family efforts to change, she seems set in her ways.

I, for myself, stopped recently looking for work, to concentrate on looking after my Mam, purely on a volunteer basis. I wish I could improve her quality of life, but that could be down to circumstances out of my control.

Just recently my mother has had a stroke which has affected the part of the brain which controls speech and memory. Although she is recovering very well, it has come as a massive blow to both me, my family and especially my mother, who as an independent woman would like nothing better than to come home.

HOW IT IS

We may not need to lift
We may not need to bathe
Our cared for is an addict
Whom we are trying to save
We watch deterioration
We are desperate for help
The stress is overpowering
It is constant day and night
We don't off load to anyone
Only those who know too well
It is like walking on a tight rope
A constant emotional hell
We encourage, try to motivate and hope
The end of the tunnel will come into sight
But there comes a time when we feel defeat
We almost give up the fight
Amid the crying we think of death

We know others who have been bereft
We feel for them so deeply
And try our best to console
The hurt we feel so acutely
As if the departed was our own
We ponder on why this should happen
To survive when our children are gone
"If only" we say, "If only" and "Have I the strength to go on?"
Addiction is widespread and growing each day
No one is immune, we can tell you
We dream that a miracle will come into play
Wouldn't that just be fantastic
Then we come down to earth with feet on the ground
For we know we must be realistic

Parent and Carers Group (NECA)

1. My son Michael became ill with mental health problems when he was 18 years old and now 20 years later at the age of 38, we still care for him and accept that this is what we must do. Sadly Michael made a number of attempts to commit suicide and we needed to watch him, support him and protect him. His ill health has meant he has had to be admitted to psychiatric units initially at St. Mary's Hospital Stannington or the Tranwell Unit at Queen Elizabeth Hospital or to the Bede wing at South Shields hospital.

2. His treatment has been complicated and not always effective and the potential side effects of treatment needed observation and clinical monitoring.

3. Given that we were all together in this position despite frustrations, disappointments, and fears, much of what occurred was **acceptable**.

There were however experiences which were **unacceptable**, and I will outline such an occasion. During a particularly low period in Michael's life he ended up in a South Shields Police Station.

4. I went to the Police Station to seek him as quickly as possible. Although I explained and was able to give evidence that he was ill, the police persisted in charging him with drunkenness and threatened to charge me as a nuisance if I did not leave.

I later returned with a legal advisor and informed the police I would be further supported by a consultant psychiatrist and clinicians. At this point the attitude of the police changed and I was treated very differently to my earlier experience.

Continued...

Though I was treated very differently by now, including an apology from the Chief Constable, I was very angry and frustrated with the police and commented in the strongest term, also indicating they should seek further training. On release Michael spent the following 6 months in a psychiatric unit.

5. Michael later went into a care home and this caused immense difficulties with the payment and entitlement of benefits. The Benefits Agency discontinued his Disability Living Allowance as a consequence of medical personnel deciding against a further assessment.

6. We took legal advice regarding a medical assessment and while this was ongoing a tribunal reclassified Michael's benefits to a lower rate. At this time the Housing Department began to threaten him with legal action for non payment of Council Tax. We actually paid this and it was eventually refunded but not without multiple visits to Councils and getting caught up in the bureaucracy and frustration of explaining to official dome that despite often quoted principles of confidentiality etc. Michael did not have the capacity and ability to 'sort out' these issues and the whole process became a fiasco.

7. Without doubt the processes and frustration I experienced led to a heart attack and I feel very saddened that few lessons seems to have been learned about mental illness in the community.

8. Michael is diagnosed as suffering from schizophrenia and with medication keeps reasonably stable. If however anything un-toward occurs he becomes ill very rapidly.

Continued...

For instance the arrangements for benefits payments have changed and the Council tax payments have caused him great stress. I cannot stand by and I attempt to draw on my emotional and physical reserves to support and advise him in a way that lets him feel he has managed.

9. I am worried however as I am 73 years old now and fear for the future of Michael. Perhaps a simplified, electronic system of identification could be employed which could be accessed by the Benefits Agency, the Police, Local Authority, Housing, etc. in a responsible and confidential manner.

10. I feel frustrated and angry when in Benefits Assessments apparently unqualified people do assessments of people with complex needs like schizophrenia. I feel they should have specialist knowledge and training.

I can remember the day the hospital phoned, I was scared, nervous and excited. My life would be turned around, but I knew it wasn't going to be easy. My brother and I got taken to my Dad's house and we all had a bit of a cry. It wasn't until the phone rang again, we knew what was really going on. They had a new liver, a match to my Mam's. Her voice on the phone made me feel a bit sad, but I knew she would be better soon. Her voice, she was excited, but also sounded quite frail.

The operation took twelve hours and that night I found it hard to sleep. I woke up early wondering if everything had gone to plan. I was allowed to visit her, the smile on her face, I had never seen her so happy. A new mother I thought but there was still a lot more to be done. She is a lot better now, and back to work. The progress she has made is excellent. The one year anniversary has past, but problems still arrive. There is light at the end of the tunnel and I am very lucky for mine!

A Young Carer

The Real Cost of Caring

Trying to “have a life”

Happiness when small things go well

Empathy helps, sympathy doesn't!

Resigned to missing out

Enjoying and appreciating the simple things in life

Always trying to make the best of a difficult situation

Life is more of a wrestle than a dance

Coping with other peoples attitudes

Opportunities are restricted for so many reasons

Strength to cope with another day

Tiring both physically and mentally

Often reflecting on what might have been

Finding the energy to cope with and face another day

Constant Care

Asking for help is hard

Recognising the important things in life

Intrusion into your home by countless professionals and agencies

Not wanting to look to the future

Gateshead Crossroads – A Break from my Caring Role!

THANK YOU

MY MAM

I love my Mam

**She loved me, worked for me, did without for me.
She loved me, fed me played with me, protected me,
cried with me.**

**She loved me, took me to school that first day, and
silently shed a tear.**

**She gave me all she had,
Celebrated my successes,
Supported my disappointments,
Soothed my bruises,
Healed my hurts,
Laughed at my 'crushes'.**

**She loved me, was proud when I started work,
encouraged me, protected me, guided me in this adult
world.**

**She loved me, loved my new love and let go of me
with a quiet tear when I took a wife.**

**She loved me as independence grew and my need of
my Mam diminished.**

**She loved me, loved my children, gave what she
could and then gave more.**

She loved me when dad died and she was alone.

**She loved me when I was confused, torn but told me I
had a family and to go home, she would manage.**

She loved me, old and grey, sad and in pain.

Oh God – I love her!

Continued...

Help me to be patient, to understand and when I go 'home' after work, tired, weary, preoccupied, stressed through my complicated professional life, help me to be patient about her life.

Her kitchen is the centre of her universe. Her TV is the world about her.

Help me to share her thoughts that seem to be so trivial.

Help me to go in and come away without feeling intolerant and guilty.

I give her so little after what she has given me.

I know I haven't long.

My family can do no more.

Perhaps someone else to care and share

Just to help me do what I should do but – do it better?

Perhaps to share my pain?

Perhaps to help me cope?

She loves me and I know this old lady is a wisp of whom she was.

She makes mistakes now. The nurse, GP and social workers are kind but confuse her, even in doing their best. Thank you.

Help me to show the love that I have.

I am pulled by my family responsibility and work.

Help me to protect her with good company and loving care.

But I honestly cannot give more

She loves me – help me to make the final walk together and on that day to know I have done my best.

I love my Mam.

MY BROTHER

I get upset when kids outside pick on him and sometimes he plays his music too loud so I can not get my homework done and sometimes he gets mad when he can not find his games because he shouts at me.

When he wants something to eat I need to help him to turn the oven on and the grill, microwave and read the numbers and help him with his dishes too.

People look at him sometimes. I help him when he can not do things and he plays with the 2 dogs. Sometimes he needs help with the dog food tins and can not cut things like paper and with his temper and he stays in his bedroom when he comes in from school he goes straight upstairs for the rest of the day.

Jessica Sales aged 13

MY SISTER

I feel different from all my friends because of my sister.

People always seem to stare when I go out with her.

This makes me upset and angry because they don't see her as a normal girl.

Sometimes I can't do the things I want to DO. I get really worried when she goes into hospital.

This will be happening soon but it will be good when she comes out, because she won't be in so much pain, which means she will be happy.

Siobhan Foy age 11

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