

# GLYN HARRIS AWARDS 2004



The Glyn Harris Awards are organised by CancerCare in memory of an educational professional who made a major contribution to the organisation. The aim is to encourage new writing which sheds light on the experience of cancer from a personal or professional viewpoint. The Awards take place every two years, with a panel of judges undertaking the challenging task of choosing two winning entries. The 2004 awards were no exception, with an exceptionally high quality of submissions from around the country. Below are some edited

highlights not only of the winners, but of a number of other entries which the judges felt deserved a wider audience. It is intended that these will be available in full on the CancerCare website at a future date.

Application forms for the 2006 awards will be available from May 2005. For more information contact Sue Tyson at CancerCare on 01524 381820. CancerCare is a registered charity which provides care and support for cancer patients, their families and carers in north Lancashire and south Cumbria.

## ALPHABET by Alison Michell *Winner: Personal Category*

**A** is for August, the month when all the trouble started. **A** is for Appointments and for Anxiety. **A** is for Anaesthetic, putting me to sleep for the Anterior section, where my innards are parted, and for the Anastomosis which joins them back together. **A** is for unexpected Adhesions, best avoided. **A** is for Atropine, deadly poison in the wrong hands, a fierce injection which counters side-effects but paralyses my tongue. **A** is for a disappearing Appetite. **A** is for the Abutilon with perfect Apricot blooms in my garden ... and **A** is for Attitude, so important in dealing with what follows.

**B** is for a Body sorely Bruised but showing great powers of recovery. **B** is for Bottoms and Bowels, not parts people like to mention. Nor do they like to talk about Blockages, which produce Bile, better out than in. **B** is for Blood, taken for testing and put back to boost strength. **B** is for Breakfast, my best meal of the day and for Booze, now allowed in moderation. **B** is for Baldness, luckily temporary. **B** brings me Bad moments, but more often a Bright side too ... and **B** is for another Birthday, a day I thought I would not see.

**C** is for Cancer. The hardest words begin with C, like Colorectal, the seat of my problems, and Chemotherapy. **C** is for Complications which mean another operation

and, inevitably, another Catheter. **C** is for Constipation, unfortunate effect of chemotherapy, and for Colonoscopy to check what is going on inside. **C** is for Convalescence, for the fresh sea air in Cornwall, and for Cricket, hot sunny days at the Oval. **C** would be for Cure if they could find one. **C** is for the Challenge confronting me ... and for the Courage I need to face it.

**D** is for Diagnosis, the moment of truth that stuns me to silence and leaves me Daunted. **D** is for the Doctors who save my life. **D** is for Drips and Drains, and for Drugs which make me Dizzy. **D** is for Diarrhoea, and for Dignity, impossible to maintain. **D** is for Dying, but not for a long time. **D** is for Doubt and Depression sneaking up on me in the night ... and for the Determination with which I meet the next Day.

**E** is for Endurance and for Encouragement. I need both when faced with Enemas. **E** is for Epidural, a great post-operative painkiller. **E** is for E-mail, keeping me in touch with family and friends. **E** is for my Eyelashes which fall out and for Eyebrows grown pale and skimpy. **E** is for Energy in short supply ... and for all the Extraordinary things there are for me to learn.

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**X** is for X-rays, for good news or bad. **X** is for Xmas, time for celebrating with my family and decorating the tree and ... and **X** is for kisses at the end of a letter.

**Y** is for Yellow, colour of hospital blankets, of daffodils and freesias. **Y** is for the extraordinary Year during which all this has been happening ... and **Y** is for saying Yes to all that life has to offer.

**Z** is for Zips, which won't do up after operations ... and **Z** is for Zzzz, for all those naps and the pleasure at last of being back in my own bed at home.

ALISON MICHELL is 58, lives in South London and has two sons. When cancer was diagnosed two years ago, she discovered that this was the start of an interesting - and ongoing - journey. Surgery and chemotherapy have brought remission, punctuated by frequent checkups and scans. After a busy career she has decided that there is more to life than commuting to a City office every day. Instead she keeps busy with family and friends, with her house and garden, and of course with writing. She helps in her local cancer charity shop on Mondays and recently took part in a sponsored walk to raise money for cancer research.



# MAKING A DIFFERENCE

by Helen Scott-Davies,

(Chair) on behalf of the Patient Carer Partnership, West Anglia Cancer Network.

Winner: Professional Category

....Cancer is a six-letter word. How it gets delivered varies greatly from one individual to another. There are no written procedures. What you get is what you get (including cancer!).

I would like to say here how impressed I was with the delicacy with which my news was broken to me. Unfortunately I can't. It was blunt and direct and came after the 'investigations'. These included having some stranger fondle my breasts and confirm that something wasn't quite right (correct term – needs investigating), followed by the indignity of having to squeeze my two breasts (note the plural) into a vice (correct term -mammogram) to then see said 'needs investigating' breast on screen being injected with extremely long needle (correct term - fine needle biopsy). Surprise, surprise I had the impression that something was wrong.

This was also my first foray into medical speak. Here I would learn the harshness of the English language – hard, lump, invasive, jagged, calcium, deposits, tissue. Why was I not hearing cysts, soft, benign, squishy, and squashy? I went away for the weekend with a sense that my life (or death) had literally metamorphosed.

To cut a long story short ... the Patient Carer Partnership (West Anglia Cancer Network) was formed. It established clear terms of reference, a work programme and elected a Chair. This was me by the way, much to my surprise and amazement. I had not been backward in coming forward in my views and it must have shown. I accepted the voluntary role. Don't forget, in my head, being involved would keep me well.

Our list of moans and groans grew. We debated and discussed. We listened to one another. We respected each other's views. We heard of the NHS constraints and demands. We had lunch and got to know one another. We heard anecdotal stories. We laughed at some stories. We gasped at others. Slowly we took shape and reviewed and refined our list. Patient empowerment, an emotive statement ... what could we, as patients, do that would make a difference?

We reviewed our list and returned time and time again to .... Breaking Bad News.

*Patients will be informed of their diagnosis (and on other occasions when bad news is given) with sensitivity, dignity and respect.*

*Health professionals will communicate with patients/carers particularly where children and parents are involved in a friendly as well as sensitive manner.*

*Patients/carers will be made aware and agree with the method adopted to inform them of their diagnosis.*

*Extract from "Standards for Professionals Breaking Bad News"*

The manner in which we, as patients, had received our news was unacceptable. Even the professionals present were shocked at our stories. There was my story, illustrated in the opening extract – diagnosis indicated over the phone and then following confirmation of surgery being led back through a waiting area with onlookers to a 'Police Incident Room'.

Other stories emerged. For example: How about receiving a diagnosis on an open ward with junior doctors all gawping at your reaction and other patients and visitors to the ward in earshot? Or consider

the insensitivity of the consultant who couldn't wait five minutes for his patient's husband to return from parking the car before giving a diagnosis!

Ask yourself ... if you were being told you had cancer, how would you want that news to be given? It's not rocket science. It's simple – with respect and with dignity. This became our starting point. Could we create a standard for how bad news is communicated and if we could, would it be implemented?

Flush in the knowledge that patient empowerment and patient involvement were key to the West Anglia Cancer Network we set to work and drafted our own standards. These were taken to the Network Policy Board, and following a few minor alterations (and a major debate on whether our standards should be Breaking Bad News or Communicating Significant Information) were implemented as policy across the Network in the summer of 2002. We were jubilant. As patients we had been successful in making a difference. We had a voice. We had changed the system to the benefit of future patients. We had achieved something.

# ALL YOU CAN DO IS LOVE HER - A Mother's Cancer Journey

by Anne Wawszczyk

Highly Commended

In the early hours of the morning on Wednesday, 18th September, 1986, Paul, my husband, and I truly rejoiced as we held our new born daughter, Ruth, in our arms for the first time. The long and painful hours of labour were forgotten as we thanked God for this precious new life which had been entrusted into our love and care. As we watched the sunrise through the hospital window, it felt as if nothing could take away the joy and wonder in our hearts. Fourteen years later, in the dark of night in June 2001, I gently held Ruth's hand as I watched powerful, yet highly toxic, chemotherapy drugs being infused into the veins of her emaciated body and I prayed that I would not have to go through premature labour pains of birthing her into eternal life! As I prayed, tears trickled down my cheeks and, from the depths of my pain and powerlessness, I cried out to God that I just wanted to make her better. It was as if He came and stood by the bedside and looked at both Ruth and myself with eyes full of compassion and said, quite clearly: 'You can't. All you can do is love her.'

Less than a week prior to this, Ruth had been diagnosed with a rare form of very aggressive lymphoma. We had been told that unless she began a harsh course of intensive chemotherapy as soon as possible, her chances of survival were slim. The 'Cancer Journey' had begun!

During those early weeks and months of treatment, it felt as if we had been plunged into a raging torrent and it was a case of simply surviving each hour and each day as we were faced with 'living with cancer. Survival and recovery were all that mattered. Our values were not so much challenged as put into perspective. For most of the time, we take life for granted - now we realised just how precious a gift it is - and especially the lives of one's



ANNE WAWSZCZYK is 52. She and her husband Paul have three children, John (20), (Ruth 18) and Stefan (15). Anne was a secondary teacher until the birth of her first son, since when she has been a full-time wife and mother. She suffered from CFS and Addisons' disease for 14 years.

children. In the Bible, we are told to "choose life so that you and your descendants may live, in the love of Yahweh your God..." (Deuteronomy 30 19) Prior to Ruth's illness, choosing life, especially in relation to our hopes for the children, had centred quite a lot on looking to the future, on equipping them for a career and helping them discern what was right for them - now all this faded in importance as we realised just how precious is the very gift of life itself - the 'being' rather than the 'doing'. So much seemed to have been stripped away from us - and yet we realised how truly rich we were as a family - rich in love.

There have been many times during the past three years when we have felt very much as if we were, as a family, on the edge of a deep abyss, yet it is perhaps only since Ruth completed all her chemotherapy that the enormity of all that she has undergone has really hit us. Our old, familiar landscape with its well travelled pathways and familiar landmarks has been devastated and we are learning to adapt to a new territory. As we look around, we recognise the remains of once strong edifices which once dominated our landscape but now lie shattered. A new landscape is emerging but it will take time for us to feel fully 'at home' in it. Meanwhile, we have to tread carefully and find new pathways, new landmarks, new 'ways of being' - and allow ourselves time to be healed of all the bruises and wounds suffered during the earthquake. We know that there are 'no guarantees' and that we cannot know just how this new landscape will finally take shape, but it seems that what is important is to trust and to hope and to continue to believe in the ultimate power of love.

# A WALK IN THE PARK

by Dan Savage

Special Award



CONFLICT



CHOP



DRUGS

The images on these pages are by Dan Savage, a young artist from Lancaster University. They come from a body of work he created in response to his experience of testicular cancer in 2003. Entitled *A Walk in the Park*, the series was selected by the Glyn Harris Award judges for a Special Award. Dan writes: "The work is presented as a chronological diary, a very personal record of the journey through testicular cancer and cancer treatment. My work is created using layers, and is concerned with layers of meaning and levels of consciousness. The body of work is split into two distinct media. The first is a series of charcoal self-portraits, incorporating print, text and handwriting. The second is a series of red enamel paintings on clear plastic film, revealing layers beneath where the enamel has been wiped or scratched. All of the enamel pieces show a whole figure; introverted, concerned with self, but more representative of the anonymity experienced during illness."



HELEN SCOTT-DAVIES was diagnosed in 2000 with breast cancer, a month before she was due to be married. Helen's married life began with radical surgery, chemotherapy and radiotherapy. Since being diagnosed Helen has been an active member of the local cancer support groups in Bury St Edmunds, Suffolk. In 2001 she was elected Chair of the Patient Carer Partnership Group (West Anglia Cancer Network), a role that she currently still serves. Helen is a regular speaker at seminars and conferences giving a patient perspective. Throughout her treatment Helen kept a video diary which became the subject of a BBC Anglia production 'From Here to Uncertainty' in October 2001.

## Fourteen Years On by Brenda Rowley

### Victor Smith

Inside the consulting room a deep voice came from the background: "Take a seat will you". I listened intently to the sound of a scrubbing brush working its way over fingernails. The previous patient must have been a mucky one. The voice materialised as a slight figure in a starched white coat. "I believe you work in the hospital?" Lunchtime's cold beef and salad lay heavy in the pit of my stomach, was it indigestion or fear? "Yes sir" I replied.

"I'm Mike Frampton, one of the Consultants, I understand you have a throat problem" I nodded in agreement, my mouth had gone dry and I was aware that a chill had entered my veins, the air conditioning must be set too low. "Let's take a look shall we? Pop up into the chair" There was a vague resemblance to Mastermind, but this was no light-hearted quiz programme. With a piece of gauze he caught hold of my tongue, pulling it forward he inserted his mirror to the back of my throat. "Mmm, I see". With that my tongue was released. I swear he'd held it down under his foot. I swallowed and rearranged my jaw. "Something very nasty down there Victor". Again I nodded. "I could tell you that it might be benign, but I don't think you'd believe me. "I had a feeling that this was one of the key moments in my personal history. I tried to breath slower and deeper. Looking over Mike's shoulder I saw a large picture of one of the latest nuclear submarines. "You a submariner?" I questioned, changing the subject whilst my overheated brain caught up. "I was a few years ago, that was my last boat" "My last boat was Ambush, that seems a lifetime ago now". "Just a bit before my time," replied Mike This was the moment when I tossed a coin mentally and decided that this was a man I could trust. If the crew of a nuclear submarine could put their faith in him, that had to be good enough for an ancient diesel-electric sailor. Two days later a laryngoscopy confirmed his diagnosis.

*"Once inside the bathroom I lit up a panatela. My last I supposed. To mark the occasion it was a good one, something a bit special. If perchance it had been rolled on the thigh of a Cuban maiden I wasn't going to complain. Enveloped in a cloud of steam I heard the Ward Sister knocking on the door and enquiring if I was smoking. I remembered the immortal words of Kipling "A woman is only a woman but a good cigar is a smoke." Sister departed, no doubt I'd hear more later."*

On the third of February I put the cover on my ancient Remington typewriter and left the office. Taking a short cut to 'Admissions' I checked in. Greetings were exchanged and I was wished the best of luck. I very much hoped so. I had no intention of shuffling off my mortal coil, certainly not dying at work. There were lots of things I wanted to do, but dying in harness like a worn-out old Clydesdale horse wasn't one of them. My idea of fading away was more in line with a deckchair

on the beach, the sea gently swirling over my feet, the sun on my shoulders and my stomach full of smoked trout and Guinness. Mike came to check that I was still willing, the time was finalised as "About eight thirty if I get my breakfast on time". It was good to know that one of us would start the day on a full stomach.

VICTOR SMITH... in his own words: "The writer is in his late seventies. After an illustrious Naval career which covered a quarter of a century he became a Chef and Restaurateur, gaining a local reputation for first class food. Twenty years later in life, he developed the symptoms of cancer. It was not a surprise as whilst in the Navy he had always drunk his rum neat and had been extremely fond of a good cigar. Eventually it resulted in a Total Laryngectomy, 16 hours of surgery and almost five months in hospital.



I concentrated on its treatment. I had a modified radical mastectomy of the right breast followed by a lumpectomy on the left side. A course of radiotherapy followed. It might be thought that this was a terrible period in my life but my abiding memory is of the great friendship, care and even laughter that I knew at that time, though there was also anxiety, discomfort and some pain. I do not regret the experience. Life was a challenge, a journey into the unknown and I was fortunate enough to travel through it and return to fitness. I

believe that it gave me a greater appreciation of my normal good health and sympathy with those less fortunate.

..... My recovery was perhaps helped by the humour I found in hospital life, though not all of it was intentional. I can still picture a fellow patient who sadly had serious internal problems. She returned from a visit to the toilet, a tall thin figure in a fluffy dressing gown. Flinging her arms wide and with a broad grin on her face, she announced, "I've been." I could not resist doing a cartoon entitled, "Happiness is- I've been!" She appreciated the humour and requested a copy of the drawing. Soon other patients wanted a personalised cartoon relating to their stay in hospital. Nurses supplied me with funny incidents on which I could base sketches. I must emphasise that this does not reflect my courage but rather my somewhat hysterical reaction to the fear that I was trying to hide. One visitor unintentionally supplied me with a title for the diary I was keeping when she advised me to regard the mastectomy as "Just a one-off affair." She never realised the double meaning of what she had said and called for a nurse when my laughter became uncontrollable.



*"I know I said she was to have bed-rest but could use the comode, but that wasn't what I meant!!!"*

Cartoon by Brenda Rowley

BRENDA ROWLEY: "Born in Warrington in 1927, I have lived in Newport, South Wales, since I was eight. I taught in seven Newport schools in a career lasting thirty-eight years. For exactly half that time I was a head teacher, a way of life which I loved. Now retired, I have many interests, including writing, art, music, gardening and family history."

