

A Celebration and Thanksgiving for the life of
Glen Shorey

30th December 1993 – 26th January 2019

The Sandpit Theatre, Sandringham School, St Albans

followed by committal at London Road Cemetery

Friday 22nd February 2019

Celebrant: Mary Porter of Humanists UK

Music: Daniel sung by Elton John

Welcome and Introduction

On behalf of his family may I welcome you to this two part ceremony where we are celebrating the life of Glen Shorey and saying farewell to him.

First, here in this theatre in this school that Glen attended and where he met many of the friends here today, we will be honouring and giving thanks for a life well-lived - a life that has touched so many people. Following this we will be moving on to the cemetery for the committal where we will say farewell to Glen. If there is anyone here who would find it difficult to go to the cemetery, everyone will be meeting afterwards at the social club to continue sharing memories and celebrating his life. The details are in the order of ceremony.

Glen was anti-religion, struggling with the concept of a benevolent god, but would not absolutely rule out the possibility, so having this humanist ceremony is the nearest we can come to meeting his wishes. While this is humanist, it is for everyone here whatever your beliefs and there will be time later on, when we have a minute's silence, where anyone with religious beliefs may say a private prayer if you wish.

This ceremony is based in the belief that we have just the one life and so we owe it to ourselves and those around us to live this one life well and, as far as we can, help others to have a good life too. In these terms, in fact in any terms, Glen lived a very good life.

As you will all know, he was determined, pragmatic, strong-willed, fearless and uncomplaining. This was despite having a condition that, in one sense, completely limited his mobility, limited his independence, and in the end limited his life. But Glen lived his life as if there could be no limits to what he could do, to what he could manage, to what he could control, to what he could experience, and, above all, to what he could enjoy. And on top of this it was not all about himself; he stood up for a more humane society and was a powerful advocate for the rights of others too.

Glen lived his life with the belief that life is too short to waste time worrying about this. He spelled this out in a blog post three years ago. His family has asked for this to be read out as it is in Glen's own words and demonstrates how Glen taught us all that life is for living. Even in death his message can live on and is something we can all learn from.

About death... written by Glen on Wednesday 18th November 2015

So, the subject of my first blog post back following a brief hiatus is a bit taboo and of course upsetting to most people (except psychopaths which, believe it or not, IS NOT me). What I am about to say may come across as a bit harsh or close to the bone, especially after what happened in Paris last week, but it is true and I just wish everyone would accept reality.

The fact is that we are all going to die (#BreakingNews). 'Wheelchair Boy' could do a Stephen Hawking and live longer than what the experts predict but the probability is I won't make it past 40. Obviously I could pass away at any point in life, whether it is the Friedreich's Ataxia finally getting the better of me or something like a car crash being the cause. I just think so be it; there's nothing I, nor anyone for that matter, can do.

That's why I am not comfortable with the whole scaremongering by the British media following the attacks in Paris on Friday. Yes, acts of terrorism are horrific but they do not mean life should stop. I have tickets for the European Championships in France next year and it did cross my mind that I should perhaps return the tickets. Then I thought you simply cannot live life if you are scared of death. I know people who have died in accidents. Should I not go out just to be on the safe side? I also have read about people choking to death. Should I just avoid food and remove my tongue? Saying that, if I do not eat I will die so I am screwed either way. There is simply not a way anyone can avoid death.

I doubt I will be quoted in years to come but my philosophy is "embrace death before death embraces you". Death is a terrible thing and is unfortunately part of life so accept that it is going to happen at some point because that way, you can live without fear. It goes without saying people want to put it off for as long as possible but do not let it become the main focus in your life. My attitude is continuously questioned but I am willing to bet that at least one of those 126 victims in France was unbelievably health conscious; did not drink, did not smoke, always ate healthy food, exercised regularly yet still died which proves that death can strike anyone at anytime.

Worrying about death really is a waste of time.

Bye for now!

It is so true - Glen embraced life as if his only fear was that he might waste the life that he had. So this is what we are celebrating today. Yes his life was far too short – but he packed so much more into it than is packed into many others’ three score years and ten.

But while we are celebrating Glen’s life today this does not mean that you won’t be mourning too. It is natural that you will be sad. It is deeply sad to lose your son, brother, nephew, cousin, friend or comrade, especially when their life is cut short. So your loss cannot be comforted away with easy words.

But what we can say is that Glen’s death will not end your relationship with him: it simply creates a new type of connection – a connection that is based, not on his physical presence, but on memory and love. You will never lose his love and his belief in you: that will remain within you for ever. As long as you remember him, as long as you love him, as long as you honour his values and the lessons you have learned from his life, Glen will live forever in your hearts and minds.

The poet Brian Patten puts it better than I can.

*How long does a man live after all?
A thousand days or only one?
One week or a few centuries?
How long does a man spend living or dying
and what do we mean when we say gone forever?

A man lives for as long as we carry him inside us,
for as long as we carry the harvest of his dreams.
For as long as we ourselves live,
holding memories in common, a man lives.*

If you go on treasuring your memories of Glen, go on talking about him, remembering his dreams, and as he did, live your lives to the full, his memory will be there for you as a source of strength.

So let me now talk about his life.

Glen’s life

Glen was born on 30th December 1993 at Watford General Hospital to Paul and Ellen Shorey. He was brought up here in St Albans with his brothers, Adam and Gavin and his sister Rachel, with his sister Michelle living close-by in London for a number of years.

Glen went to St Michael's Church of England primary school, in St Michael's village. It was while he was there that he was experiencing the early stages of Friedreich's Ataxia. By the time he was 11 he was using a wheelchair.

He was strong-willed from childhood - a characteristic that served him well throughout his life. Even when young he made his own mind up – for instance only ever eating what he chose to eat. He was fearless too. He loved wrestling; Gavin his younger brother remembers his dad always having to tell him to be careful not to hurt Glen. Glen didn't seem to worry about it.

When he received his diagnosis at the age of nine, after a period when he would keep falling over for no apparent reason - he took it well; at least he now had an explanation, something he could now deal with. He showed the same pragmatism and practicality then aged nine, the capacity to face up to things that he demonstrated throughout his life. He never complained about it.

He wouldn't ever give up. He always loved football - when he was younger he would be bombarding his dad to kick the ball about with him. When he lost strength in his legs, rather than giving up football, he started playing in goal. He got himself an electric wheelchair from Whizz Kidz so that he could race around on it while Gavin raced around on his bike and later on he got a wheelchair that he could play football in.

When the time came that he had to move to senior school there was no question of him not going to Sandringham, the same school as his older brother Adam. So thanks to his parents' insistence changes were made so that he could attend. He made many lifelong friends at school; including with Sue and Sandra his teaching assistants who went on to become close family friends.

He enjoyed many school trips – to the Peak District, to France and to Germany. Although he did once refuse to go on particular roller-coaster at Alton Towers, he seemed to be fearless. When he was only 16, he did a sky-dive, raising £4,500 for Great Ormond Street Hospital. This was just a week before he had to have an operation.

Glen did well at school and was given an award for perseverance. He was of an academic bent, taking Philosophy, History and Media Studies at A level. He was determined to go to university and, having gained excellent grades, he took up a place at Brunel University in London to study sports journalism. While he was there his heart became affected and after one term he decided to leave. He had always said he would be lucky if he got to 21; always aware that his life might be limited he

decided that he couldn't put his life on hold for three years. He had to pack as much in as he possibly could. And he did.

Being away just for those few months gave him the experience of independent living and as soon as he was back home in St Albans he set about trying to get his own flat. It took some time but in 2015 he was able to move in. He bought everything for it himself –all to his own taste. He loved entertaining there. He loved people dropping in. He would have people round for barbecues and he would put on a Christmas dinner there for the family.

He took charge of his care, employing his own care team. It was hard for Ellen, his mum, who wanted to care and protect him - but for him it was part of being an independent adult – and as he said, by living independently she could be like the mum of any adult. So he advertised on Gumtree and made sure he had carers with whom the chemistry was right. He was young, he was sociable and he wanted people he could go out and have fun with. He would interview them, give them a probationary period so they could find out if they were compatible and if they didn't fit, they were gone.

He managed to get his own car through Motability and also a special hoist so that - with a carer driving him - he could sit alongside in the front seat, just as any one driving with their mate would do. They would drive with the music as loud as possible, and would go to Southend or Brighton just for the day. He went to several Wireless Festivals – where he would manage to sit right in the middle; he always wanted to be in the thick of everything, so he could, as he put it, “soak up the atmosphere.”

He loved going to shows, to stand-up comedy, to the cinema, to concerts, to pantos. He especially loved pantos; he could fit six of them into a single season. And brother that he was, he would always tell Adam that the ones he had seen were all better than the one that Adam was in.

When Adam and Claire married last year he was best man with Gavin. Glen organised the stag do, including all the activities himself. He loved everything about the wedding. He wrote the best man's speech with Gavin. So many people have commented on how witty and clever it was and how it was such a special highlight of the day - and we are soon going to be seeing some film of him there. Just two weeks before Adam's wedding he went to the wedding in Italy of his carer Michael, getting there with Rachel, Gavin and his dad Paul.

He led as normal a life as possible. He took great care in his appearance – he never wanted to look unkempt – he always wanted to look smart – his clothes had always to be colour- coordinated. He kept himself as strong as possible for as long as he could - doing armchair yoga, going to the gym, building his upper body strength. In fact when he applied to go on the TV show “The Undateables”, he said they refused him as he was not disabled enough – which in fact also happened when he was younger and was playing Boccia and he went to a tournament in Farnham and was told he was not disabled enough for that.

He really lived life as if life was precious – too precious to waste. He never let the fact that he was in a wheelchair stop him from following his beloved football team, Arsenal. He wrote about most matches on his blog. He went all over Europe following the game; he even went once to Paris for the day with a carer to see a match. He visited very premiere football ground in UK and wanted to visit most of them in Europe.

He went on many holidays - for instance he went with the PHAB group to the Calvert Trust on Exmoor where he abseiled in his wheelchair, and he went sailing on the Norfolk Broads and he went on a lads’ holiday to Lanzarote. Saying life was too short, he never wanted to go back to the same place twice. So many places to go –so many experiences to pack in!

And when he wasn’t out and about he would be playing Fantasy Football with his Dad, his brother Gavin and his Uncle John. He was so knowledgeable about football - he was like an encyclopaedia - they often won. He was competitive in all things, whether it was sport or PlayStation or the quizzes that he took part in at the Rose and Crown. He created a family board game called “Five Second Rule” – and he usually came out on top. In fact he was undefeated this past Christmas.

Glen loved TV and watching films – in the cinema or at home on Netflix with a takeaway. He loved EastEnders and documentaries about murder – especially ones where they exposed injustice. He cared passionately about this.

He was a powerful voice for social justice, for disability rights and was a member of the Disability Access Group. He didn’t just put up with things if they possibly could be improved; he complained when things weren’t right. Faced with speed humps on the Verulamium cycleway that tipped him backwards in his wheelchair because they were the wrong height, he persisted until they were taken away. Having had difficulties on the train his complaints to Thameslink led to him being consulted by

them. When he went to a football ground where his sight was obscured he would write a critique. He was always fighting for change.

He was an active member of the Labour Party and passionate about the NHS. There was one march where he got hold of a megaphone and was shouting “health before wealth.” He insisted that everyone he knew should vote to make a difference. One of his last things he talked about in hospital was to ask if Theresa May had resigned. He had been in hospital for a number of days and had been cut off from his social media and news feeds.

So we are come to the end of his life. But before I talk about this let me read one other piece from his blog:

This was written in June 2012 when he had experienced a painful procedure.

Now, I am telling you about (this) not only because it's a humorous anecdote (imagine my little face wincing) and I want to boast what a brave 'Wheelchair Boy' I am, but because it also provides the perfect metaphor for life. To my brothers' dismay, I did not scream or chicken out. I manned-up and got through the pain which mirrors my attitude towards life. There are times when everything seems to be going against you but, as I did yesterday, take a deep breath and continue. For me, this is the only way that people can live life because pain and heartache will never disappear from the world. It's just a game that you have to triumph.

And he did triumph. In his last days in hospital with a chest infection – aware as always that death could be waiting around the corner for him – he stayed awake for four days as if he wanted to win that game too, taking charge, being in control, taking off his oxygen mask to ask about his oxygen level. At the end, in his own time, he was calm and unafraid and he died peacefully surrounded by the family he loved.

Glen was a true inspiration for all who knew him.

Let us now look at some video memories of Glen. This has been lovingly put together by Gavin, who was not only his brother and carer, but was also his best friend.

Video Memories of Glen

I will now read some tributes to Glen.

Glen's Godparents, Donna and Trevor

It was an honour for us to have been asked to be Glen's godparents. Every time we saw him I would tease him and with a cheeky smile he would look at me and we would always have a laugh. It has been an absolute privilege to have known Glen, and over the last 25 years we had some brilliant times together. Glen will leave a terrible void in our lives and be so truly missed.

A poem written by Mitchell Ladbrook, a friend from primary school.

My Friend Glen

 Fallen petals beneath your feet
 You would never back down to defeat
 Your voice is calling me
 Don't know if I'm falling
 Or soaring too high
 Shimmering lights in the sky
 It's now time to say goodbye
 You'll always be in my heart
 With no ounce of death
 Just a bright light that will never fade
 As long as you're here in my thoughts
 You'll always be remembered as a friend
 This is for you 'Gooner Glen'
 One day I will see you again.

A Tribute from Glen's family written by his brother Adam

For Glen, as I sit down to write something I had hoped I would never have to write, the screen of my iPad barely visible as the tears stream from my eyes, the one person who I know could help me to write this is no longer a phone call away. What a privilege it has been to be your big brother, to watch you grow, to share in your successes and to be by your side in the hard times.

Many will talk of your bravery, and how inspiring you were, they will speak of your intelligence and wit, you were a remarkable man. But Glen, what you gave this family runs so much deeper, you gave us so much happiness and love. You were cheeky, you were funny, you gave us strength, you pulled us together.

There is a sad irony in the fact that your heart failed you, because you never failed to have heart, you loved life, even though it presented you with so many obstacles. You were always so thoughtful, particularly when giving people gifts. Who can forget the ski lesson for Rachel? And the hats with dangling corks you gave Clare and I before our trip to Australia. But you gave us the most precious gift of all, a brother we could love and cherish and priceless memories that we will hold in our hearts forever.

I'm not sure how we carry on now, but there will never be a day when we don't think of you, I will speak to you every day and please know you were loved beyond words by a family that adored you. Our Glen.

His sister, Rachel

I am honoured and grateful to have called you my brother. We had such amazing times together and you have taught me so much. You were my world, my strength, my friend, my brother, my advisor and my inspiration. There are not enough words in the world to thank you for being such an amazing brother. You will always be in my heart and I know you will always be with me until the day we meet again. I know if you were here now you would say 'Oh Rachel grow up!!'

Life's for the living and I will live it for you now.

His brother, Gavin:

Glen. Not just my brother but my best Friend. There is soo much I could say about you or about the time that we spent together but instead I just want to say thank you for being you. I have always been proud of everything you have achieved and gone through, but last year when I stood next to you during the best man speech as you made the room erupt with laughter I have never felt soo proud in my life and I will never forget that! On that day everyone got to see how hilarious you are and I feel soo grateful to have been able to see that side of you every day, which I will miss more than anything. I love you and will miss seeing you smile back at me every day.

For one final time as I would say to you before you went to sleep. Goodnight my friend, goodnight.

Reflection

We are now going to have a minute's silence where you can think about your favourite memories of Glen, the treasures that remain because of his being in your life or any things you would like to thank him for. And if you have a faith you might want to use this time say your own private prayers. This will be followed immediately by a visual tribute.

Visual Tribute

Music: You are always on my mind sung by Elvis Presley
and Sweet Caroline sung by Neil Diamond

We will be leaving soon to go to the cemetery, but before we do I will read this message from Glen's family.

Thank yous from the family

Thank you to all of Glen's carers, many whom are here today. Whether you were with him for a long time or a short time, please don't ever underestimate the impact you had on Glen's life. You enabled him to live as independently as he could and allowed him to live life to the full and we will always be grateful to each and every one of you.

Thank you to Glen's teaching assistants from secondary school, Sue and Sandra. You both saw Glen through highs and lows and were a constant throughout. He may not have always shown it, but Glen thought the world of you both.

Thank you to Teresa. You have been a tower of strength, helping us to plan today, getting Glen dressed for the final time and leading him today. You have brought us so much comfort at this difficult time.

Finally, the family would like to thank all their relatives and friends who have rallied around them during this difficult time. From food parcels to floral tributes and cards, thank you all for your continued love and support.

Recognising that people may wish to make a donation in Glen's name in place of flowers, the family has decided that any donations received, either today or through the undertaker, will go into one general fund that will be divided between five charities that assisted Glen at different times in his life. These are:

Whizz Kidz – who got him his first electric wheelchair.

Make a Wish Foundation – who gave him a day out when he was first diagnosed.

Caldwell Children's Society – that gave him the special wheel chair that he could play football in.

The Willow Foundation – with whom he went to the Eastenders set and

Remap – who made him a table for his wheelchair.

Now we will be leaving to go to the cemetery. As we go we will be hearing

Music: Laura Branigan singing Gloria

Committal at London Road Cemetery

At this time, when words say so little and tears say so much, we gather to return to the earth that part of Glen that cannot remain with us; and we remember with gladness that something of him will forever live on through you who had so much love for him.

It may be of some comfort to consider these words of Philip Pullman in the Amber Spyglass.

Even if death means oblivion, friends, I'll welcome it, because it won't be nothing; we'll be alive again in a thousand blades of grass, and a million leaves, we'll be falling in the raindrops and blowing in the fresh breeze, we'll be glittering in the dew under the stars and the moon, out there in the physical world which is our true home and always was.

So now it is time for us to say farewell and thank you to Glen, surrounding him with love as we return his body to the natural world from which we have all come, and to which, in our time, we will all return.

Glen because you loved, others loved, and will love.
Because you laughed, others laughed, and will laugh again.

Because you fought for fairness and justice, others will fight for fairness and justice
and your fight will continue

We cherish the memory of your character and your strength and your determination
to not waste a minute of life that is so precious.

Now with thanks for all that you have given us
And all that you have shown us about living life well,

With respect we say farewell.

And with love we leave you in peace.

Into the freedom of wind and sunshine,
into the dance of the stars and the planets,
into the safe keeping of the universe,

We let you go.

Glen will be a part of this place for all time.

Through the freshness of spring
the warmth of summer,
the mists of autumn,
and the cold of winter;

He is at peace.

Glen now lives on in the hearts of those he touched. May you go on from your pain of separation to strengthen each other, to face the ongoing tasks of life with courage, with love for each other, and in remembrance of the good and happy times you shared with Glen. Keep him alive in your memories, talk about him often, keep telling those stories.

Now, the best of all answers to death is the whole-hearted and continuing affirmation of life. So his family now invite you to join them in the social club for refreshments and to share more memories and continue celebrating Glen's life.

Go well.

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