8

Why?

Soon after he had made the decision to end his life in April 2009, Craig bought a diary and composed a 30-page, handwritten letter to his parents, transcribed here.

To my beautiful parents

When I think back on my life and my ongoing physical suffering and pain and all the other non-related health ups and downs, I know with 110 per cent surety that I would do it all again with all the NF1 issues, if it meant having both of you as my parents. You are both wonderful and beautiful in your ways.

Dad, your loyalty, commitment to the family, your willingness to always put yourself last (almost to a fault), the quiet love shown through your actions reminds me of a song I used to listen to when I was young.

The chorus went "love is not a feeling but an act of goodwill". I always thought this to be true, but like a fool, I only realise now that you, Dad, have been living with this as your mantra (maybe not consciously) every day of my life from birth.

There are so many memories of our lives. For example, you living next to me in the tiny room in London, to your never-ending support in my golf career (while it lasted), to your commitment to my vocation studies, which I never got to carry out because of health issues. You have a beautiful heart, Dad.

Mom, my special, beautiful mom. I don't know how I would have coped emotionally without you. Not many, if any, mothers and sons share the emotional bond we have. Despite efforts by many to say that it was an unhealthy, overly involved relationship, we, rightly or wrongly, maintained it.

"WL4.1"

I could never have coped without the soft, feminine love that only a beautiful gem heart can give. I truly believe that if I could decide to do it over again without NF, but had a different mother without our loving relationship, I would choose having NF1 and all that goes with it if it meant I could experience your love, angel love, not from this world love.

Even the strongest soldiers grow weak, and as a very wise and great man who happens to be my uncle and my godfather recently said, "Nobody knows more than Craig himself how much he has suffered."

I honestly feel I have played my hand well in life. I would have "folded" much earlier were it not for the two of you, my beautiful parents.

This disease has raped me emotionally and physically, violently and brutally, and repeatedly throughout my life. Our personalities develop from childhood and reach a plateau of growth and basically then that's who we are, bar a few changes from events that mould us differently.

I truly feel that Craig, the true Craig, has been slowly but surely eroded over the years of my illness, which has been my whole life from birth to now and has been drastically accelerated over the last number of years.

Now the true Craig (Craig beyond his body) is so tired he is barely there and I want to leave peacefully before he has vanished.

Many feel that things happen for a reason. Some believe this as well as the fact that we are all given challenges in life to make us stronger.

Well, I have been broken all the way down, from my challenges in life.

DKI

If I could ask people to ponder one point, it would be to consider the possibility that even the camel, as the well-known saying goes, had a last straw that broke its back.

I am fully aware of the pain and the suffering as well as the poverty in the world. There is so much suffering and everyone on earth has their problems. Physical pain and the level of its severity is a self-perceived thing, we all experience physical pain differently, what one person can take is not what the other can stand.

I am not going to grin and smile and say that things are fine. I deeply admire those who have the ability to do that. I am now beyond the point of caring what other people outside of our wonderful home think. They will never understand what I have had to go through.

People look at me and I look normal. I ask them to look at my medical history and all that goes with it and the imminent arm surgery as well as the adhesion forecast, not to mention the unpredictability of NF1 and how my quality of life has changed.

Those who have known me all my life know how I have coped and, even now, with increasing health challenges, know how the real Craig has changed.

Craig is hardly Craig any more and I want to go in peace before the little bit of me that is left has gone.

I wish with every fibre of my being that I was stronger but reality cannot be changed. This is such a sad thing but if we don't know how to accept reality then we live in denial as the famous Serenity Prayer goes: God, grant me the serenity to accept the things I cannot change; the courage to change the things I can; and the wisdom to know the difference.

I have tried my best to change the things I am able to. And have fully accepted those that I cannot and, yes, I know the difference. It has got to a point where I have been forcefully put in a corner and bricked in and to top it off, the bricks are falling and caving in on me, bruising and destroying me.

Mom, angelic Mom, thank you for always telling the doctors

that your little boy had a problem with headaches that you, Mom, were not imagining.

I feel no anger towards NF. It has just got to a point where enough is enough and I no longer want to be abused.

Mom, thank you for always believing me when I told you things about my body and how it feels. Like how I told you about my colon, months before it happened. I know you and Dad believe me about my arm. Even pulling a blanket that brushes over it causes pain and how now, at times, I feel it in my fingers.

Dad always said that I never complained without reason.

The big fibroma on my scalp at the front of my head causes throbbing pain at times; thank you, Mom, for believing this and that I am not trying to find things that are wrong or that I am constantly trying to scan my body.

If I could leave a thought or lesson behind it would be that it is okay to sometimes say, "I have had enough", particularly when a person has had a long period of fighting, whether physical or emotional.

I also would like people to realise how stupid it is to sometimes say, "I know exactly how you feel." We all have different pasts and emotional make-ups and live with different challenges. I know everybody has problems, but some are indeed greater and everybody deals with situations differently.

If I could ask one thing it would be that people should be slow to judge me. For them to try to imagine the possibility of a challenge that is not a constant thing, a challenge that is variable and one that has and is affecting many parts of my body.

Perhaps if I had a disability that was constant I would have been able to endure it more, but I cannot keep adapting.

I would also like people who have relatively normal bodies to be more consciously thankful for them. Some people want things like face lifts and enhancements when they are perfect. Yes, if it makes you happy then do it, but be thankful firstly for the blessing of a disease-free body.

Please tell people not to judge a man until you have walked

NF1

in his shoes, as George [Irvine] put it. I feel that my challenges have not made me stronger, they have made me weaker and I want to go to sleep before more of who I am is taken.

Dad, please take Mom for a skinny decaf cappuccino once a week at Woolies. She loves their cappuccino's taste and all that foam so much. Also, remind her to use her stamp card to add up to a cappuccino on the house. I used to love going weekly with Mom for one, but as NF further hammered me, we have been doing this as a take-away for the last two weeks.

The two of you will have to do whatever it takes for you to cope afterwards and whatever maybe, it's okay and it's your right; all I can say is thank you for listening to my heart talking and not judging me or saying something selfish or using some warped psychology.

Dad, thank you for the letter. All of those things were learned by watching and observing you so, it's more of you and how you raised me than my own doing. Would you please make allowances in your wills for a substantial amount to go to a NF1 Association in my memory and let them know how I died, so people can see what NF can lead to in certain individuals?

I ask also of you the following and I obviously will never know if you have done this, but Mom has in fact given me her word. When the deed has been done, tell people at my funeral about my medical history and how I have suffered physically for my entire life and that in the latter stages I faced surgery and adhesions. Tell those people how much was taken from me.

Please tell those who said you have to stop me and who questioned how you could allow this, to ask themselves who it would have been better for?

I can't imagine being a parent having to go through this, but one thing I do know and believe is that when you have a child, you give up certain things, one of which is doing things for selfish reasons or for being able to manipulate that child once you have raised him in the best way possible, to accept him for who he is and to support him in rational decisions.

Tell people that even if you said to me that you were not going to allow this, I would have gone without your blessing. Then you would have felt regret. Some people are saying that you will regret this.

I would like them to think deeply about the regret you will feel if I went with someone else to Dignitas and not my parents. The regret you would feel if you were not there as I breathed my last breath. They must think how I have suffered and be at peace that I, for the first time, am at peace, something I have searched for my entire life.

Sometimes, Dad, I am not with you when you talk to people. When they ask how you feel about this matter, you probably raise your problems with me not being terminal. All I ask of you is that in these discussions you mention that I do in fact have an incurable disease, that I am badly affected but by it as well as all that goes with it.

Dad, you have said on different occasions that in your opinion Mom and I overstate how I am affected; this is the opposite of my opinion and I feel you understate it to people.

Dad, I know this is extremely difficult for you because naturally you are a fighter. I thank you so much for your support. I want to thank you so, it is beyond words. It is more a tidal wave of love and gratitude pouring from my heart for supporting me in your own way this far and for what is to come. Just always remember my dream of finally being at peace in all senses of the word – it is or can be, could be a comfort to you eventually.

I love you both for the parents you are and have been. All of our hearts are breaking and I just want to sleep, be at peaceful sleep.

Just remember support is given in different ways and both of you are individuals and give support in different ways. The support you give is equally vital to me and I want to thank you for that.

PKI

From: Brian Gilbertson
To: Craig Schonegevel
Sent: Wednesday, 6 May 2009 11.46 PM
Subject: What I want both of you to know

Dear Craig
Thank you so much for your email. How well and movingly you write. You should have tried a short story or two, or kept a serious diary. I sometimes wish I had done those!

Now I want YOU to know YOU have influenced and enriched the lives of others in many ways, over many years. Do you remember your extensive advice to me when I wanted to buy a rowing machine a long time ago?

And your detailed instructions on how to use it correctly? And the "bicycle crunches" that you made me do to strengthen my "core" muscles? I heeded you, and am much better for doing so; but if only I had followed your advice more intensely and consistently than I did, I might today have had a physique approaching yours!

And then your swimming initiative was amazing to me; I have always wanted to swim well, and I even had a coach for a while when I lived in Melbourne, for there was a fine but largely unused pool in the basement of the building. But even with that, I could never have contemplated taking up the challenges that you did, in the open ocean and the Knysna lagoon, and I admired you for that.

And perhaps you know that Quinton ran the London Marathon two weeks ago? Who would have imagined that! I did a marathon ONCE in Johannesburg, and it was an important marker in my life, for it brought to me a painful awareness of my physical limitations, and I vowed never to try again. Yet Quinton has committed to run AGAIN next year, and he will do so solely because of and for you: He will run on behalf of an NF charity. And he will be a better and more complete man for having done so!

And then I was intrigued by your discovery of (serious) music, your judgment on Bach (my all-time favourite, even if not yours), and the development of your own musical skills. And so on, and so on...

But above all, we, my family, have admired you, so much more than words can say, for the courage and stoicism with which you have borne your personal cross over so many years. We would have given almost anything for it to have been otherwise, but your cup could not be passed. Your strength and dignity, and indeed those of your parents, throughout your suffering have taught us humility, compassion, of the frailty of human existence, even gratitude, for we were not given your burden to carry.

"WL4.2"

Today you fill our thoughts, our hearts, our prayers. May you find relief, peace and solace.

With Love
B

From: Craig Schonegevel
To: Dr Howard Nock
Sent: Sunday, 10 May 2009 12.22 PM

Hello Doc

Doc, because you are very dear to me and mean more to me than you will ever know, I'd like to share the following with you. Doc, this will shock you and I don't know how I would handle being on the receiving end of this email. All I can ask is that you keep this to yourself and respect that it is a very personal decision that I have made entirely on my own and that this decision has given me true peace.

For a while now I have had discussions with George Irvine and he is of the opinion that it is the true Craig that is thinking and not a depressed or disillusioned Craig.

My health just does not give up and I should have already been to Cape Town to have the operation to my arm. (I feel it has grown in size since I've had the MRI and it is causing more pain as well as giving me pins and needles in my fingers all the time.) I have been unable to have the op because my colon is playing up again. I was in hospital again for an obstruction 10 days ago,

DKI

which thankfully passed this time. I am still basically on liquids. Adhesions have formed again and it is just a waiting game until it leads to surgery again. The scar down my entire abdomen has been cut six times now and the irony is that each time more adhesions form that again lead to surgery. There is no cure for this problem, like there is no cure for Neurofibromatosis, the disease that I have.

I have decided and this is the part that will shock you... to go to Dignitas Clinic in Switzerland, which is an assisted-suicide clinic. I have been in contact with them and am submitting medical history and other forms.

If they accept me (subject to certain conditions) I get a "green light" to travel to them and be assisted. This is legal in Switzerland. The thing is that my parents will be travelling with me and may face legal issues when they return. They respect my decision. They have been advised to approach senior legal counsel. There have been a few cases in the UK before, Daniel James went there and his parents were charged but the case was later dropped.

After 12 operations and the pain I have experienced and the imminent surgeries that await me, as well as all that goes with my disease, all I dream of is peace. And to not have the true Craig further and further "raped" to the point that what is left of him will be gone.

Love
Craig

PS. Doc, if I do get the "green light", please accept that I have included you in my Will.

From: Dr Howard Nock
To: Craig Schonegevel
Sent: Sunday, 10 May 2009 10:21 PM

Dear Craig

I was deeply saddened to read your email but at the same time I appreciate that you have found a peace that I'm sure you have not known for a while now.

I feel very touched that you have shared this decision with me. At all times when you have shared your medical problems with me, I have been struck by your courage and strength and how you still take time to think of others. So you have my utmost respect.

Please feel free to email me at any time with any thoughts you may want to share.

Please know that my thoughts are with you and your family.

Your friend
Howard

From: Bruce Robertson
To: Craig Schonegevel
Sent: 21 June 2009 07:30 PM
Subject: My Friend

Dear Craig

First off, let me tell you how much I appreciated your call on Wednesday – most especially because you chose me to share your thoughts and decisions. I have known for a long time that you are ill, and about the nature of your condition. And so, I have respected your personal space, and have only enquired rarely about how you are. So, your call came as a surprise to me, but what you had to tell me was perhaps less of a surprise. And no less of a surprise was the manner in which you shared these most personal thoughts and feelings with me. Let me explain.

DKI

danger for the moment – 49 pills were not enough. I knew also that it was only a matter of time before he would succeed.

I remember wondering if Patsy would survive all the heartache and stress that goes with the destruction of an inseparable relationship between mother and son.

George arrived quickly and with him he brought calmness and love. Craig was not fully conscious as we carried him to the car. This was a short journey to a medical facility, unlike the very different journeys Patsy, George, Sandy and I had each walked with Craig and indeed he walked with us.

The doctor on duty was outstanding. He was non-judgmental and caring. After he was stabilised, Craig came home again.

"WL4.3"

14

Craig: In His Own Words

During the four months that Sandy spent interviewing and photographing Craig, she often emailed Craig lists of questions or thoughts that came to mind. The following is a selection from their correspondence.

From: Sandy Coffey
Sent: Monday, 29 June 2009 2:08 PM

In all mainstream religions, including Buddhism, suicide (assisted or not) is a no-no, with regards to afterlife. Are you worried about that?

x

From: Craig Schonegevel
Sent: Monday, 29 June 2009 7:10 PM

No, I feel more at peace now than I ever have in my life with regard to both my health situation, as well as religion and my relationship with the heavenly Father in my heart.

The fact that this is assisted suicide does not make me want to "sugar coat" things and say that it is not suicide because

DKI

ultimately it is exactly that. By drinking the barbiturate I am taking my own life.

Firstly, let me state that I believe that what I have decided to do is in a way different, not correctly or incorrectly, but different. Often with suicide the person is looking through a "frosted window" and acts out of desperation or a depressed mind. I am of sound mind and fully believe that this is the way to go.

So too does the depressed person believe fully that this is the only option. In this case people have no right to judge this person, because they have not lived his/her life and do not know that this act was right to him/her in his/her heart and head.

In the case of the depressed person, though, my wish is that they would have had time to work through their issues with a professional and perhaps by taking medication to help them. If they then still feel that this is the only way to go then it is their personal decision.

The last thing I want to do is end my life in a violent way, e.g. shooting myself, because if there is a botch-up then I will be worse off. Also the anxiety that goes with this is great. I have had enough of anxiety with my condition to add more in my passing. So too has enough violent hurt been done both to my body and spirit. I don't want my body to be violently hurt, whether it kills me or not, as my body and spirit has been repeatedly subjected to great violence.

To answer your question. I know that for me, in my heart, I fully believe that access into the afterlife will not be influenced by suicide, both in a depressed state or sane, assisted or not. In the end, I fully believe this to be the right decision.

I could be wrong though, and I believe that in the end then it will be just that in God's eyes, a wrong decision. God does not punish us when we make errors of judgment throughout daily life.

I also believe that there are some things that God cannot change as much as He may want to. It is then that we must trust

our heart and follow what it "whispers" to us to be the way.

Hope this gives some indication, Sandy. Please forgive me for the long-winded response.

C

From: Sandy Coffey
Sent: Monday, 29 June 2009 8:33 PM

Can you describe a "perfect" day if you could have it?
And then describe your day now?

From: Craig Schonegevel
Sent: Tuesday, 30 June 2009 10:39 AM

A perfect day for me?
Sometimes we catch or experience a glimpse of true happiness and fulfilment. The thing is I wish that these moments could be bottled and we could live in that feeling or experience constantly. This is not reality though, and each and every one of us must make the best of what we have at our disposal or what we can do to contribute.

I experience moments of true happiness very differently now to before. When I lie down on my bed and I am free from emotional and physical pain with my mom beside me, for that short while I feel totally at peace and this is what I believe the place that I will be going to will feel like constantly.

So, my perfect day would require this feeling constantly, feeling total love, acceptance, peace, being pain free, being anxiety free and not having to live in the box that NF1 has put my mind and body into where I am limited to a fraction of the person I once was physically and emotionally.

A perfect day would also entail people being understanding and respectful of the difficulties I face and allowing me to cope

NF1

in the way that is best for me, not what they believe is best for me.

My day now?

Having taken the decision I have has brought me a peace that I have never known. Sometimes I get very anxious though; I wish that things would move faster. I get anxious that I may not get the "green light", although a large part of me knows that I will.

If I don't, I have to go for arm surgery, which will have a six-month recovery period. My true self (my spirit/heart) will have a much longer recovery period though. The recovery period is for the rest of my existence on earth, that is the extent to which the constant invasive surgery affects my being.

In a perfect day I could eat normal foods as well as not be concerned about it potentially causing an obstruction in my colon, which ultimately gets me under the knife again.

In a perfect day, I would not have to subject my family to the torment of this disease, because ultimately my mom and dad are carrying the burden as well. A perfect day would entail my heart being held by loving hands that "get" me completely.

A perfect day for me would be lying on the bed at Dignitas and know that peace, to know I was loved by those in my life who matter to me.

On that day I would like to know that I did matter, that I did make a difference. On that day I would like those special few to know that for the first time in my life I have found something that I can do that cannot be taken away from me by Neurofibromatosis.

I would like them to know and experience my peace, whether they are in the room or not. Whether they know the exact day or not. I would like them to know that I am okay.

From: Sandy Coffey
Sent: Friday, 3 July 2009 5:44 AM

Given the amazingly beautiful and close relationship you have with your mum, you know your assisted suicide is going to be the hardest thing she will ever have to face. Can you give me your thoughts on this?

From: Craig Schonegevel
Sent: Friday, 3 July 2009 12:53 PM

This action will break my mom more than I will ever know. I can only take the strength she is displaying as a lesson in that the hardest thing of all is letting go of somebody you love with your whole heart, your whole life and for whom you live and to allow them to take this action.

I have said in my long letter to my parents (which they have read) that it is okay to say I have had enough, whatever that may personally mean and if it helps. It is not admitting defeat.

I have told my mom how the "angel love" that she has given me all her life was so pure and without it I would have perished long ago. Without that love I would have been a wreck who never experienced total love as God intended.

So, I am privileged to have received such love as most don't and that in fact it was good that other people never gave it as it could never have matched up. I can only hope that the same feeling of love (she has given me) and how beautiful she is crashes over her daily, numbing her mind.

She, like me, is a private person. I know she, like me, loves the sea. I know she, as she has told me, does not want to carry on living in the same townhouse and complex that we currently do, that she needs a new beginning.

She also has said that she wants solitude afterwards. I have told her this is okay and to ignore people who say this is wrong. I dream that she can move into a flat like at The Bay or

PKI

Summerstrand No. 1 complex and look at the sea constantly and be left alone by the interruptions of townhouse-complex living.

I hope with my whole heart that with each wave that breaks outside her windows is my inconceivable love, soul medicine that is coming to thank, comfort her, love her, hold her. That like the sea our love is constant even though I am not here.

From: Sandy Coffey
Sent: Friday, 3 July 2009 5:46 AM

Can you tell me the moment you knew there was something seriously wrong with you?

What does Fear mean to you?

What does Courage mean to you?

From: Craig Schonegevel
Sent: Friday, 3 July 2009 12:17 PM

As I am not a specialist in the field of the mind and how it develops, I do not know at what age a human can take in or sense things. So, I believe it was much earlier than I answer you, but to me this was when I knew serious things were happening to me.

I remember having the most terrible headaches at ages five, six, seven and all the vomiting that went with it. How my mom had to phone the library and apologise for books spoilt by vomit.

Unfortunately there were those who did not pay attention to my mother's instinct when I was having severe headaches. She just knew that there was a very serious problem.

Somehow I ended up in Dr Wickens's office for the first time and he suspected a brain tumour and said, "Book a plane ticket to Cape Town when you leave my office. I am phoning the professor at Red Cross now!"

When we left his office and entered the lift, I sensed there was a big problem with me. I did not understand the French that the adults had spoken but my spirit knew. As the lift rode down, so too did the tears from my eyes come down as I knew I was very, very sick.

Fear has taken many forms in my life and I suppose many children have the same fears, like of the guys at the school, baddies, who inflict hurt like violence on the world.

The older I have become, the more my fears have tapered off into one: I fear Neurofibromatosis (mainly because I am one of those who falls in the group with life-threatening problems).

I fear its unpredictability. I fear the constant growth of more and more fibromas on my body, because ultimately with every one that grows on the nerve end, the chances increase that it's a major nerve.

I fear my stomach condition, the adhesions that lead to the most destructive colon operations, both for my body and mind.

I fear more of the current suffering I experience and will experience. I fear dying in pain, from whatever form of death. I fear living with Neurofibromatosis and the colon condition that I have, [what it] has meant for my life and will still mean in the future.

I fear solid food because ultimately it is the cause of blocking in the narrowed section of colon that has formed. So, I take in mainly liquids leading up to Dignitas.

I fear current pain, more pain, suffering and imminent surgeries.

Courage, to me, means taking control of your life and ignoring what the masses and some friends say and taking the action that you know to be right and follow through.

Courage is also admitting your faults. Also it means loving somebody, as well as loving them enough to let go of them.

PKI

From: Sandy Coffey
Sent: Friday, 3 July 2009 5:41 AM

How will you like to spend your last 24 hours on this earth?

From: Craig Schonegevel
Sent: Friday, 3 July 2009 7:12 PM

A time of total peace with mind and body. Not to have a "bedtime" as such but if any one of the three of us falls into a sleep it would be okay. To keep conversation in line with what our hearts and not heads are thinking. To listen to my favourite classical music albums/pieces, whether in the background or other times, as the focus.

To look out on nature (the Alps hopefully) or a picturesque view and just hold one another or listen to the music quietly. To just lie down at times holding hands, breathing.

To go for a walk in silence breathing in the clear air. To drink hot tea at a fireplace and just ponder whilst staring into the flames. To talk of how we will hold each other until we meet again.

From: Sandy Coffey
Sent: Wednesday, 8 July 2009 10:55 AM

Can you tell me what it feels like to finally have some control over your life?

I know you don't want to think about it, but if you don't get the "green light", what will you do?

From: Craig Schonegevel
Sent: Wednesday, 8 July 2009 5:47 PM

If I don't get the "green light" I will make a plea to Mr Minelli. Even if it means that I will have to fly over to Switzerland to have a meeting with him. I will just talk from the heart to him, not a planned speech, just from the heart and ask him to listen with the heart. If this does not work I will have to find a doctor who has a heart for my suffering and wishes to help me privately.

He must act out of free will, it will be a great risk to his career and future, but all I will be able to say from my heart to him is that my soul will be eternally grateful as I hug him with thanks. I will sob in my heart with thanks.

For the first time in my entire life I now can be in the driver's seat. That brings peace, comfort, certainty, rest and bliss. The "green light" has not yet appeared and that brings uncertainty but once it has shone, I will follow it to this state of inconceivable bliss.

From: Craig Schonegevel
Sent: Sunday, 12 July 2009 6:48 PM

Sandy
Just to let you know...

Today I took down more beautifully framed pictures of my past coping mechanism (swimming) from my wall. I will be buying two poster-size blank cardboards tomorrow and be writing a mantra I have made up to help me cope to get to Switzerland. My dad walked into my room while I was doing it and seemed angry with me. (I think this just makes the situation more real to him and he battles.) I battle in my own way too and have to do this to cope.

He (my dad) then said I was going to damage the frames by how I was lying them down. (I think he is honestly just battling

OK I

Wednesday, 5 August 2009 7:20 PM

It is noteworthy that this email was written by Craig a few weeks before ending his life and yet he uses words such as "stable", "connected", "peace", "sound mind", and "rational".

Emotionally, I have never in my life been more stable than I am at present.

Spiritually, I have never in my life been so connected and at peace with my God as I have been for the last while.

Psychologically, I am of sound mind (which many will confirm) as well as completely rational.

It is sick to expect anybody to carry on accepting, adapting to being operated on and for there still to be no cure. We live in an age where we do all sorts of things but science can't benefit me.

Tuesday, 4 August 2009 3:25 PM

Lately my dad has been "pecking" me on the head when we say goodnight. When I am lying on my right side in bed and it is my left side of my head that he pecks I feel virtually nothing. It is numb along there because of the fibroma that was removed along the nerve that runs on that side. There are more fibromas also growing in the same area.

Wednesday, 5 August 2009 3:42 PM

I want to say to mothers who say when they read the book: "How could this child do this to his mother?" – I want to say to them what I have already said earlier: That the greatest love is to love somebody so much that you are prepared to let go. This cannot really be understood as our love and situation is totally different.

When I go through all the pain and operations and new fibroma growths, and emotional trauma, when I live my days with this incurable disease that has affected me GREATLY, it violently rapes and destroys my mom's heart, spirit, mind, body, soul, life, present, past, future, child, purpose, reason. I could go on and on and on and on but I shall refrain.

Those words could NEVER illustrate how destructive this force is.

It has taken a while, but my mom looks back now on my past, my present and future and knows that this is the right decision that her son has made.

Another thought: My mom has been using the perfume "Angel" for the longest time... Not only is the name applicable to her because it is what she is to me, but it smells so different on her from others who wear it. Her skin was created for it. It brings me much comfort. When I am sick I ask my mom to spray some on my pillow.

Thursday, 6 August 2009 7:13 PM

Many people may think I should be booked into an institution when they hear that I have a suicide plan if Dignitas has not got back to me. The thing is that I am totally in control. And it would be insane to expect me to endure this kind of torture for much longer.

Sometimes the best thing people can do is to do nothing, just to quietly support... People naturally want to call and visit and give time and counsel and suggest you do this and that.

My mom and I are much the same in this regard, we like to be quiet by ourselves or have the very close friends around, people who totally "get" us and how we function. Some of the things they think are best for us are exactly that: what they think. Only we know what we really need, if we are totally in touch with our true self. I accept that they do things with the

DKI

laughter when I gave my dad two shirts, one saying, "If I gave a shit you'd be the first person I'd give it to." The other has a male and female stick figure on it. The male, who is holding a parcel, says to the female who is holding a pot plant: "Nice bush", and the female says, "Nice package."

Tuesday, 18 August 2009 4:04 PM

My attempt failed over the weekend. Just when I find a way to cope it is taken from me or fails me.

I will persevere though, until the deed is done.

After the last operation I was in this semi-private room (which thank God I was moved into because my mother complained after eight people were visiting the one bed next to me during the first half an hour of my arrival from intensive care). The name of the man in the new semi-private room was John. He was old and had the softest spirit; I think he and I could have been best friends in another life.

He was suffering and was full of bedsores. I used to always reassure him of things. We were on the same meds for anxiety. When he asked me what this medication's name was because he needed some, the one nurse shouted at me for "infecting" him with the need for the tablets. When he left the hospital he was moved into a hospice-type place near his home in Grahamstown, where God, please, let that sweet soul get some proper affection.

Later on his wife phoned my dad and said that John had told her that "Craig was the best roommate he had ever had!" Sweet John.

Last night I had a horrid nightmare. John and I were being cut, cut, and crying while the horrid nurse shouted at us.

Wednesday, 19 August 2009 7:27 PM

The exceptional choice of language used by Craig in this email, 13 days before his death and four days after his unsuccessful attempt, are a clear sign of the extreme anger and frustration he was experiencing towards both NF1 and Dignitas. Every day, every hour he would check the computer to see if Dignitas had an answer for him. He could not understand that Dignitas, of all organisations, could put him through such agony. His frustration at Neurofibromatosis eating away at him also just seemed to grow.

I am so f-ing angry with this disease.

Nobody should have to endure this disease if they are affected to the extent I am or even worse.

I have just found more fibromas. There were already three pea-sized ones on my hands near my fingers, so today I find some on the palm of my hand.

They are not just "on-the-surface" like some NF1 sufferers get, but entangled in nerves, the hard type. God, I just can't keep up and in future still more growths like this.

I will not, I cannot accept this! In some cases this condition should be seen as terminal by the medical fraternity in which case the sufferers should have access to morphine in order to terminate their lives.

My deep desire for the badly affected ones I leave behind is that they don't have to suffer in this undignified way; my heart will be crying for them when I am in "paradise". I don't want them to have to go through the anguish of having to find a "way" as I am doing.

Plan A (Dignitas) is the preferred way, and I am only giving them a very short while, Plan B (overdose of Dormonoct – 49 tablets) did not work, I have a Plan C firmly in place, I have given it my own name, I am calling it "Plan Pravda"*

* Craig erroneously thought *Pravda* meant "freedom". When translated from the Russian, it means "truth" or "justice".

PKI

Pravda, Pravda, Pravda, Pravda, Pravda, Freedom, Freedom, I will fight on for my Pravda!

Wednesday, 19 August 2009 8:05 AM

I am a peace warrior, I am fighting hard, I am working hard at my Plan C. Plan A is still best but it seems so... I deserve PEACE and I will not let go until I can fall slowly, softly, peacefully into "sleep".

When my dad affectionately stroked the bottom of my left foot yesterday morning and I did not feel it, he said, "Was that not ticklish?" (It's kind of like when a GP tests your reflexes and strokes the bottom of your foot with an "implement".)

My dad said he wondered if this had anything to do with the removal of the saphenous vein from my left leg when I was at Great Ormond Street for my second operation. I have always noticed that my left foot/leg has a bit of a different gait.

I found three new fibromas in the fulcrum of my arm this morning (the crux area on the side of elbow). I showed them to my dad and he said this will probably make it difficult to draw blood; my dad never speaks "junk" and knows that it is an issue.

My dad also said this morning that society has it all wrong. How astute! I cannot even be granted my peace when I am in a terminal state for the rest of my life.

Thursday, 27 August 2009 8:04 AM

It has now been confirmed that 30 Dormonoct should have done the job, I took 49, story of my life...

When I was born in 1980, my parents had just moved from Johannesburg to Port Elizabeth. With them they brought their

dog, a Doberman named Vodka. He was such a gentle dog to me as a baby. Little did I know that my last days would also be spent having a favourite drink on each day which is Vodka based. Here's to the Moscow Mule.

This morning my fingers are getting the pins and needles sensation again, and then it switches to intense pain in the upper arm. Last night, or yesterday I should say, I had four packets of the laxative, Movicol, as I know my body, and all the indications that a narrowing is getting narrower. I won't be crude and mention in words all the indications I have picked up.

I am getting very weary now. I will implement Plan C (Plan Pravda) in the not-too-distant future.*

Saturday, 29 August 2009 5:08 PM

How is this – after what Dignitas said yesterday – and further research shows Plan C must be changed, as I cannot risk another failure. Despite the assurance of a lot of info, Plan C will only cause me future suffering, so Plan C must be altered; my God, where is the grace?

Now even when I go to pee I bump my fingers on a tangled-up fibroma, and being on liquids for so long has lead to another haemorrhoid, a bad haemorrhoid!

For F*^*^g hell, where is the grace for this little abused boy who wants to just go to sleep, that is his only wish?

* On Friday, 28 August, Craig telephoned Dignitas and was informed that he had not been given the "green light" as the paediatrician to whom his case had been referred had suggested that NF1 "does not cause death". Craig was asked to resubmit his application with further medical motivation, a task he thought was "futile".

DKI

From: Sandy Coffey
To: Craig Schonegevel
Sent: Monday, 31 August 2009 6:19 AM
Subject: today

Hi Craig, got all your messages – being stuck out in the bush with very limited reception is terrible. I felt very far away from you. I also got your message about not wanting to see anyone today, and I completely respect that. If you change your mind, I can and will be there – you know that I am with you in spirit and love and light.

Sandy
x

From: Craig Schonegevel
To: Sandy Coffey
Sent: Monday, 31 August 2009 8:01 AM
Subject: Re: today

I am going to write a thought of the day now, Sandy...

I am pleased that you got back safely. Sandy, I love you so very much and wish I could see you, but I have to conserve my energy for the "last haul".

C

From: Craig Schonegevel
To: Sandy Coffey
Sent: Tuesday, 1 September 2009 8:45 AM*
Subject: thought of the day

Society has it all wrong. To have to take my own life in this horrid way is disgusting after all the suffering.

* The following night Craig successfully took his own life.

They say, "Oh well, he is not terminal"... Well in my opinion I am worse than terminal... I have been terminal for nearly 29 years and will remain to be badly affected by this disease and its complications.

I hope that in 100 years people may take a grain of consideration towards this topic that needs attention. I wish this end on no man who has suffered his entire life, but this end, even though terrible in nature, is a zillion times softer than all the brutality of NF to my body!

Lastly, I wish to quote a highly qualified hospice nurse, Theresa Stephany, who wrote: "It is insulting to assume that patients who request assisted suicide are clinically depressed. Most are just realistic. They know what lies ahead and they'd rather not continue with it."

OK I

but some are very small. The book about my life will show well the contrast between the clothed Craig and Craig in underwear. Those on my spine and hips are average sized and can only be felt when they are touched by say a shift in lying position in bed. The arm is another story. It causes lots of tightness in my biceps, triceps and at times gives me pins and needles in my fingers. When I take off my shirt or it hooks, or I can feel it when I am soaping myself in the shower. Folding my arms I can feel a sort of electric shock in the whole arm right into the fingers.

love
C

From: Craig Schonegevel
To: Michael Quinton Gilbertson
Sent: 7 August 2009 17:52
Subject: Tks

Quin
For all that you have done, for all that you are doing, for what you will do, I thank you with every fibre of my being. You have a beautiful heart.

I have created my own "green light" as the manner in which Dignitas is dealing with me is appalling. Know that I will keep you in my heart always.

C

From: Michael Quinton Gilbertson
To: Craig Schonegevel
Sent: 7 August 2009 07:25
Subject: Re: Thx

"WL4.4"

Dear Craig
Never have I been more lost for words when trying to write an email. I want more than anything to plead with you to wait at the red light but I know this would just cause you more pain.

You are more of a man than I could ever be.

With much love and admiration
Quinton

From: Patsy Schonegevel
To: Brian Gilbertson
Sent: 12 August 2009 12:58
Subject: Thank You

Hi Brian
Thank you for making a special trip to see Craig.

Coming home from the Radisson Hotel this afternoon, Craig and I were both in tears. Craig just carried on saying what a beautiful heart and man you are. I could not agree more. Thank you for helping us to deal with this situation. The days are very long here at home.

You remain my soft pillow to fall on and I could not love you more.

Patsy

PKI