

# A Song for Ollie:

## How social media enables new ecologies for caring & giving

### *Norman Jackson with the help of Ollie's mum*



*'It would be lovely if you could share something around the value you see in social media for lifewide learning and developing personal and connected learning ecologies'.*

This was the invitation I received from the Guest Editors and after pondering what I might write about I turned to my own life to see what examples I might find to illustrate the value of social media for achieving something important and valuable. This close to home approach has served me well whenever I try to understand my own lifewide learning and by coincidence last weekend I organised and performed in a fund raising gig to raise money for a little boy called Ollie. So this is

a story about Ollie and his family and how they have made good use of social media to create a whole new ecology of caring and giving. Ultimately, it's a story of love, hope and charity. It's a story of how people help and support each other aided by on-line technologies that enable them to express and demonstrate their concerns, feelings and values.

#### **Ollie**

Six months ago Ollie, a bright, friendly and inquisitive two year old, was diagnosed with a nasty life threatening tumour of the skull: a type of tumour that is extremely rare and very difficult to treat. Of course the family were devastated to learn of this and they set about trying to get the very best treatment for him - a huge learning curve and life changing process for them. Thankfully, the NHS stepped up to the plate. Following the diagnosis he was treated with radiotherapy at the Royal Marsden and then sent for 3 months to a special state of the art radiotherapy centre in Florida where he was given proton therapy for 9 weeks. The hope is that with proton rather than usual radiotherapy, he will suffer less long term brain damage from the radiation treatment. The NHS paid for flights for Ollie and his parents (but not his younger sister), basic accommodation and for car hire but there are of course many additional costs, and bills at home still have to be paid so the family with the help of friends began a campaign to try to raise money to help offset some of the immediate and aftercare costs.

#### **Creating a technology enabled ecology for caring and giving**

The story of this campaign illustrates well how a whole new ecology of caring and giving was inspired by this little boy who created new purposes in the lives of many others. A campaign that was greatly aided by the social media and web 2.0 tools that have become part and parcel of everyday life. Ollie's mum describes how it all began.

*'We were hesitant at first about fundraising as we wanted to keep our privacy and I didn't want to go begging to friends but we got rather scared by predictions of how much we would spend in the USA and about the likely long term consequences that we would have to deal with and decided that doing it for Ollie was more important than our privacy. I was lying in a hospital bed next to Ollie in tears when I [decided to] set up the You Caring website page for fundraising as it was a marker of where we were at in our lives and an acceptance of the difficulties Ollie was likely to face. I then sent the link to Ollie's dad to approve before it went live. Once he gave his approval I posted the link on my Facebook page and it snowballed at an amazing pace from there. Within a few days friends had*

*organised events and my cousin was coordinating things by setting up the weebly website. She then also set up a Facebook group for Ollie.'*

So the family made use of three bits of social media to create an infrastructure to fulfil the multiple goals of raising funds in support of the additional costs that Ollie's treatment and care would require, and to enable the family to provide people with regular updates of Ollie's progress with the treatment in America.

Ollie's auntie assumed responsibility for coordinating activities. She set up the '[Ollie versus Cancer](#)' website using the weebly website building tool. The website explained the background to Ollie's illness and listed some of the events that were planned by friends to raise money. It should be made clear at the outset that Ollie's family had a strong and supportive network of family and friends who were willing to get involved in fund raising. In other words they had the social agency for creating a campaign and the technology facilitated and helped to extend the reach and sustain the campaign and draw people into it that were not directly connected to the family's own social network.

Ollie's auntie also set up a [Facebook Group](#) which enabled four things to happen. Firstly, it enabled Ollie's mum and dad to share their journey with Ollie through his treatment in America with people who cared about them and what they were going through. Secondly, it enabled the people who joined the Facebook group to show their concerns and support for the family. Thirdly, it enabled the people who got involved in fund raising to publicise their events and to inform and celebrate successes in raising money and thank the people who had supported the various events. Fourthly, the conversations and fund raising actions that emerged inspired others to get involved.



A total of 150 people joined the group between January and May and over 70 postings were made. Ollie's mum and dad provided the members of the group with regular updates of Ollie's treatment and the way he was responding to it and they shared something of their experience of travelling to and living in Florida for 9 weeks while Ollie had his treatment. The stories and the many images of Ollie posted kept people informed and also enabled the members of the group to share their love and affection with the family particularly while they were overseas. For some members of the group who got involved in fund raising the Facebook page enabled them to publicise their events which included coffee and cake mornings, quizzes, auctions, gigs and much more

The third piece of technology that was used to support fund raising and help create an ecological process for caring and giving was a [YouCaring](#) webpage to facilitate donations. There are several well known web-based giving platforms but the YouCaring platform does not take any money from donations that are made. Ollie's webpage explained the reason for fund raising and it shows the supporters and donors though people can remain anonymous if they wish to. The platform also enables people to post their own messages as to why they are giving revealing again the ecological nature of the very human process that is being formed around the fund raising campaign. The messages of support and hope accompanying many of the donations reveal the depth of feelings friends, friends of friends. They also reveal the ways and means in which the sense of responsibility to care for others reached out in an organic ecological way to people who did not know Ollie or his family. Here are some of the thoughts and feelings shared by some of the donors.

*'A small donation given with love to help a beautiful boy called Ollie who I do not know but have heard so much about from my dear friend..'*

*'As a mother of a 2 year old I can only imagine what you are going through'*

*'I read about you in the programme against Torquay and I thought you could probably make better use of this than I can.. Chin up little dude.'* From an AFC Wimbledon Fan

*'We are friends of Daniel and Laura's [not their real names] and are pleased to be able to give a donation towards Ollie's fund'.*

*'We don't know each other but I hope that if my children needed this help others would support me too'*

*'We are donating money on behalf of Ellie. Instead of buying her a birthday present I am donating money to the charity advised by her parents'*

The power of the YouCaring website in disseminating information and connecting to people is extended through twitter (used over 50 times) and with 135 other social media sites and services. By early May over 400 supporters had donated through the YouCaring webpage and their combined efforts totalled nearly £30,000 which was the goal that the family had set in January.

### **Mum's perspectives**

*It's fair to say that we could not have raised the money we did in so short a time without the help of these technologies. The weebly website was very useful as a central point to focus fundraising announcements but it also was the platform we used for an online auction that raised a significant amount of money. Facebook served as a useful medium to enable us to update those who care for Ollie during his journey with the odd photo of his smiling face and it also freed me from having to send hundreds of texts or individual emails when I really was too exhausted to do more than a few lines but felt people deserved to be involved. So many people contacted us through Facebook. An old friend from school that I haven't seen since I was 16 raised money through her work. Many of the prizes for the auction came via Facebook friends and local businesses who answered a plea on the local mums fb group. The YouCaring website enabled over 400 people to donate many of whom we did not know. We were astounded by how many people took up Ollie's cause raising money in many ways. One Wimbledon fc supporter that saw Ollie when he was mascot for Torquay United fc at the match between the two donated several times, the last being a bet with a friend that he lost about his team's performance.*

### **Tribal lessons**

I found the messages of support, love and friendship on the Facebook and YouCaring websites, and the stories of things that people had done to raise money for the family, truly inspiring. Many people had organised or hosted some sort of event like raffles, auctions, pub quizzes, bingo, table top sales, cake bakes and coffee mornings. One person had run a marathon and a group of office staff had donated their lottery winnings foregoing the pleasure of a fun night out. Ollie's illness and the journey his family are making touched many people and made them want to give and in some cases create events that encourage others to give. So that one little boy and his family's fight against his cancer has spawned a whole ecology of personal action and involvement to not only achieve the practical goal of raising money for the family and more generally for charities that are helping other children with cancer but to provide emotional support for the family and beyond this to show that our world is full of people who are moved and who care about the same sort of things.

This is a wonderful story and it shows how a horrible situation can inspire many people to do something positive and good. I suppose we all want to be involved in doing something good and belonging to groups of people who are supporting something good. That sense of belonging to a just cause reminded me of a TED talk by Seth Godwin<sup>1</sup>, who talks about the way social media enable us to create 'tribes' in order to spread ideas that are worth spreading and connect people

who share interests and beliefs. He argues that 'the internet has ended mass marketing and revived a human social unit from the distant past: tribes. Founded on shared ideas and values, tribes give ordinary people the power to lead and make big change.' His message is 'find something worth changing and then assemble tribes, that assemble tribes that spread the idea that becomes far bigger than ourselves that becomes a movement'. It seems to me that my story about Ollie and the circumstances of his life is a modern story about the creation of tribes by people who cared enough to try to do something practical to help and to show Ollie's family that they cared. In doing this the very basic human need to belong to something good (Ollie's fund raising campaign) was being satisfied.

## My own tribal story



As for me and my family's involvement. We know Ollie and his family and like many others we wanted to do something to help. I play in a band and when I told the other members about Ollie they all wanted to help so we offered to put on a benefit gig which the family kindly accepted. We threw ourselves into the project raising money by selling tickets, recording songs for a CD which we are selling for £5. We also auctioned the band for a sizeable donation and got another sizeable donation for a commission to write and recording a song. One of the band also went on local radio to talk about it. Nearly 150 people turned

up to our gig which raised £2300 for the two cancer charities we were supporting. On the night our music was some of the best we have achieved and we combined really well with two other musicians who also offered their services free. The feedback we received from people who attended was very positive and people genuinely seemed to have a good time and we sold over 40 CDs on the night! The effort was considerable from everyone involved - the band worked hard and all my family helped with the organisation and sales of drinks and making sure that things ran smoothly. I was very proud of them.



There is no doubt that the band has benefited hugely from being involved in Ollie's fund raising campaign. Our Song for Ollie benefit gig brought us together through a cause we all cared about and we achieved something we valued in the process. We were inspired by having a purpose that was greater than our own needs and interests and its influence is continuing as we try to raise money through donations for downloads of our Song for Ollie CD through our own YouCaring webpage. If you would like to be part of this amazing ecology for caring and giving inspired by a little boy who is battling for his life please follow the links below.

Song for Ollie - music downloads <http://freeworlders.weebly.com/>

Song for Ollie YouCaring webpage <http://www.youcaring.com/nonprofits/song-for-ollie/170782>

Ollie versus Cancer <http://www.youcaring.com/medical-fundraiser/ollie-lovis-vs-cancer/122800>

1 Seth Godwin 'The Tribes We Lead' Ted Talk February 2009

[http://www.ted.com/talks/seth\\_godin\\_on\\_the\\_tribes\\_we\\_lead?language=en](http://www.ted.com/talks/seth_godin_on_the_tribes_we_lead?language=en)