

Derby Road Health Centre Patient Participation Group
Meeting Held at 1pm on Wednesday October 31st 2018

Present: Rob Kirkwood, Ajanta Biswas, Jane Ward, Darshan Numwa, Harbhajan Nunwa

Trevor Clower – Carer and Founder of Nottinghamshire's Carers Roadshow

Apologies: Stephen Hyde, Dave Ward, Nikki Wood, Rupert Sadler, Hazel Sadler, Patrick Randle, Glynis Randle, Liz Lemon, Mary Stokes, Margaret Gotheridge

There was no business scheduled and no urgent business raised during the meeting.

This meeting was devoted to a talk from, and conversation with, **Trevor Clower**, founder of Nottinghamshire's Carers Roadshows. Trevor covered a wide variety of issues relating to carers and the work he has done in developing the Roadshows, which are held in a number of venues throughout the city and county, usually from May to September each year. He used a number of anecdotes to illustrate some of the problems, and solutions, that are part of a carer's life. It became clear that many more people are carers than probably realise it.

One of Trevor's main themes is that of there being a sequence of five stages that carers, without the right support, will go through. These are:

First it affects your job

Second ... it affects your social life

Third is promises to help stop

Fourth ... is isolation

Fifthis hospitalisation

Trevor also discussed the importance, with all the difficulties it involves, of discussing death, especially what happens to the cared-for person, if the carer pre-deceases them.

Please see the attached documents of Trevor's for more information.

Date of Next Meeting: Wednesday 21st November at 2pm

Five Sequences of Events

First it affects your job

Second ...it affects your social life

Thirdare promises to help stop

Fourthis Isolation

Fifthis Hospitalisation

Hello, my name is Trevor Clower, I am a carer, my son has a learning disability and autism, he is 43 years old, so that means I have been a carer for 43 years.

However, I am here today to talk about another kind of carer, the instant carer.

A person who goes through life making relationships and some get married. They form a family life with kids and a home with a job and gets on with the day-to-day things that entails.

When suddenly, without any warning, their nearest and dearest starts to act differently or a dramatic event happens, you then pack them off to see the doctor and he prescribes something and sends the patient home.

This is when, this person accepts their role as a responsibility towards the patient, someone they love, and cherish.

This is the point where the Five Sequences of Events starts to happen.

Through no fault of their own, they are sucked into the caring roll and have no idea of the enormity of what being a carer, entails.

The **first** thing to be affected, in this Sequence of Events will be the carer's job. Maybe make it part time or just leave the job completely because of the time needed to be a full time 24/7 carer.

If by any chance you can reduce the job to part time, it will not stay that way long, as the demands of being a carer, are relentless.

The **second** thing, in this Sequence of Events, the carer's social life is reduced, severely, to the point where it does not exist anymore.

Not having the spare time to keep appointments or arrangements because of the pressures of being a Carer and its demands.

The **third** thing, in this Sequence of Events, is you will find all the promises from good intentioned people to help you, will dwindle, because they too have a life to lead and they too have commitments of their own to deal with. In addition, you will get lots of advice from good intentioned people, but it is you, the carer, that has to carry out all this advice, which only adds to the 24 hours a day 7 days week care ... your already giving.

The **fourth** thing, in this Sequence of Events, is the isolation. THE WORST! You start to sleep like a cat, the slightest noise in the night your awake. You can't leave the house for more than an hour, for fear of the person you're caring for has wandered out the house or fallen out of bed or taking the wrong medication. Professionals start to talk AT you with good advice, and not listen to you or take the time to understand what you are dealing with, your already working 24/7 & unable to fit in all this good advice. This only adds to the guilt your feeling.

The **fifth** thing, in this Sequence of Events, is depression. This is when the carer, eventually, pops up on the radar of the services as a patient, for the first time, as a complete wreck. They have to be hospitalised at a cost. Then the person they are caring for pops up and has to be taken into a specialised home, at a further cost.

In that regard I am hoping that my words, here, will fall upon ears of someone who can make a difference, by intervening with this Sequence of Events, effectively.

By getting the professionals to include and consult the Carer, by asking their advice on how to administer their treatment in a way that the patient will accept and understand.

By inviting the Carer to patient meetings and listening to their problems in an open and concise way, so no one is under any illusion on the amount of work and effort everyone is doing on behalf of the patient that includes both the professionals and the Carer.

This will effectively stop the isolation accruing and it will help the Carer to feel valued and listened too.

By including the Carer from the outset of diagnosis, it will offer the professional a person who will have known the patient for most of their life. Therefore the Carer's expertise can be put to good use in the administration of the treatment and effectively make the professional decisions have a more positive result.

So finally you will have a much happier patient, and we all know a happy patient always responds well to treatment.

A happier Carer, because you have intervened with the Five Sequence of Events, and stopped them from continuing.

And with the Professional making better cost effective decisions and also keeping the Carer from being hospitalised, by simply doing what they do in a different way, this will lead to a happier accountant too.

I know we all like to hear statistics, I can tell you there are 29,000 carers in the City alone and the local authority only has 718 carer assessments on their books. So there is a large gap, in reaching these carers.

But I have no such statistics for these Sequence of Events, as I have no idea if anyone is listening to my words and implementing to intervene with the Five Sequences of Events effectively.

There is one thing I have not mentioned and that's money... no I have not missed it out... it's just that this procedure will cost nothing!

I can only hope that someone here can make a difference.

In the meantime, I will continue to give my views wherever I can.

Trevor Clower

Unpaid Carer

Award winning Carers Champion

NHS England Patients Representative

NHS England New Care Model Active Partner

Nottingham City CCG Patients Leader

Dealing with Death

Death should be talked about much more often among unpaid Carers, particularly among the younger unpaid Carers 30 to 50 year olds. As it stands at the moment death is mostly talked about among the older unpaid Carers, who often leave things far too late to set up an exit plan, to ensure the person their caring for is surrounded by a good caring package and care providers that understand the needs of the person your caring for.

This takes time to plan and set up, to make sure the paid carers are the right ones for the person you are an unpaid Carer for. Their quality of care and reliability has to be established over time, with your, the unpaid Carers, supervision, to ensure their the right people for the job. Making sure their care is effective and to help lift the level of trust, the person your caring for, has, in the paid carers and the care provider agency too.

Too many unpaid Carers leave it too late for this to be done in depth, to make it a substantial relationship. When you try to set up a care plan that has not had the advantage of scrutiny from the unpaid Carer, has the potential of not being effective over time and it's the long-term care that is important.

The reasons why an unpaid Carer has to have an exit plan in place for the person their caring for is numerous, but the main one is what comes to us all in the end, death. However, there are other reasons such as the unpaid Carers health or some dramatic upheaval, such as a car crash or some other accident, which will change the dynamics of an unpaid Carers life and leave their caring roll in disarray and no time to put things right for the future.

The scenarios are numerous, but always immediate and life changing, with little or no chance of sorting out a good exit plan for the person you are an unpaid Carer for.

One such scenario is when the unpaid carer is suddenly taken ill and then this vulnerable person, the unpaid Carers is caring for, pops up for the first time to the NHS. They have to react to ensure the safety of this person and take them into a residential home or care home.

The vulnerable person in question has lost the person that looks after them and been taken out of their home, into a place they don't know. So their alone in a strange place, surrounded by strangers, feeling frightened and confused. This will affect their behaviour from being withdrawn or frustrated to the point

of lashing out, and the care home has to cope with this, which often resorts to the use of drugs to calm them down.

Unfortunately, they will continue to administer these drugs until someone explains to the care home the true nature of their character, but if the unpaid Carer is not around, then who is going to explain?

So the drugs are administered for the unforeseeable future, subduing a patient for the wrong reasons, for weeks, months or even years.

We all think we are going to wake up in the mornings ready to start another day, but it's not a guarantee and that's why having an exit plan to look after the person you're an unpaid Carer for is essential.

It's similar to the reasons we have a life insurance or make out a will, but an exit plan takes time to plan and to ensure the plan is working with the right people involved in their care.

This is where the unpaid Carer can be most effective, by giving advice as to the needs of the person they are an unpaid carer for. As well as letting go and sit back and watch it happen with a critical eye on things, to ensure the quality of care is consistently good and if not, intervene with good advice from the vast amount of experience the unpaid Carer has in the needs of the person their caring for, to get it right consistently, giving the care plan longevity.

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