



# TAKING CARE OF MANCHESTERS HIDDEN HEROES



**THRIVE**™

Supporting Parent Carers Over 50

# Contents

A LITTLE BIT OF HISTORY	2
IN FOR THE LONG HAUL	3
TIMES ARE CHANGING	3
A DREAM REALISED	3
WHAT DO WE DO	5
Walking the Walk	5
Information & Advice	7
Carers Lunches	7
TLC & Company	8
Advocacy	9
SPREADING THE WORD	9
PEER SUPPORT	11
PARENT STORIES	12
Carrying on regardless	13
Letting Go	14
Update on Neil and Diane	15
When a Parent Dies	16
ARE WE VALUE FOR MONEY?	17
FRAN GETS THE LAST WORD	18
THANK YOU	20
HOW YOU CAN HELP	21

# A LITTLE BIT OF HISTORY

This short report is our chance to share with you the work of the Thrive project which is here to support older parent carers of people with learning disabilities. In the next few pages you will find out what the Thrive project is all about. We will also share the stories of some of these amazing parents who, when many of us are enjoying new freedom and more time for leisure pursuits are still parenting full time, and will continue to do so for the rest of their lives. Of course we also want to tell you a bit about what the project does to support these amazing people.

Most of all, this report is a testament to their resilience and dedication but we hope it will also serve as a way to make others aware of the importance of the contribution they make.

Since we began our project we have learned so much from them and along the way there has been real joy and a huge sense of privilege. There have also been times when we have felt deeply saddened and shocked by how isolated many of those parents have become and to see just how difficult their lives can be.

## **Fact:** Parent Carers Save You Money

Did you know that the cost of keeping a person with severe learning disabilities in a residential care home can be between £951 and £1,441 per week? Or put another way between £49,000 and £75,000 per year. (PSSRU Unit Costs Health and Social Care 2011). As long as these parents can carry on caring they are saving the taxpayer and the state millions!

**We think that makes them heroes but for the most part they are invisible.**



# IN FOR THE LONG HAUL

Bernie Wood our amazing manager is often heard to say “we beginning middle and end it” when parents come to us with a problem.

Being a parent carer does not have an end point, lives change from the day they discover their child has a disability. As that child grows their needs change and so does the kind of support that they require. Some parents may just come to Talbot House once but many will come back to us periodically over the years as they face new stages in their own and their child’s lives.

Talbot House is definitely not the new kid on the block; in fact we have been around for more than 30 years. We pride ourselves that in these days of brief interventions and “instant solutions” we are with our parents for the long haul.

This means we have shared in and followed the lives of many of our families all the way through.

# TIMES ARE CHANGING

There was a time when our children rarely outlived their parents but this has changed and more and more we are coming across people who we first met when they were new parents.

They continue to do the 24/7 job they were doing then but now they are older and sometimes elderly.

# A DREAM REALISED

Over 30 years ago the parent of a son with severe learning disabilities decided that she would see him thrive independently while she was still alive. That parent was Bernie Wood. Fast forward to 2014 when Bernie and Fran began to dream of a project that was dedicated to older parent carers. We also talked to the older parent carers we knew and the Thrive project was born. In January 2015 we were able to turn that dream into a reality thanks to a grant from the Tudor Trust.



## THE GOOD NEWS

Thrive is here and by providing some much deserved support it can be possible to make a real and lasting difference to the lives of our hidden heroes and enable them to carry on doing what they do better than anyone else can – take care of their children.

## THE GREAT NEWS

Spend even ten minutes with one of our parents and you will quickly realise that you are in the presence of someone who has incredible resilience, is resourceful and with organising skills that would put many a CEO to shame. All this along with a huge capacity for love and compassion. When it comes to finding solutions to the very real challenges they face they are truly our biggest asset. So we hope you will enjoy the rest of this report and this glimpse into their lives and, like us, recognise that there are real heroes among us who deserve your recognition and support.



# OKAY SO WHAT DO WE ACTUALLY DO?

And the answer is we share the journey – Yes really it's that simple like all great ideas it begins from a basic and straightforward premise. In this case to walk beside parents, not in front pulling them, nor behind pushing and most definitely not standing on a pedestal offering "Good Advice".

Later in this report we have some case studies and facts and figures for you about the services we provide and the needs of parent carers, but for now we just want to tell you in plain English what it's all about.

## WALKING THE WALK

### Stage 1: Respect The Experts

*"One of the most sincere forms of respect is actually listening to what another has to say"* – Bryant H McGill

First of all we sit down with the experts – Yes that's the parents themselves.

Secondly – We listen not just to any immediate problems that bring them to the door but to them, to their story and to their ideas, hopes and fears. Their journey

Only then do we throw our expertise into the pot – don't be misled, we do have expertise and specialist knowledge and that can range from helping sort out benefits and housing through to getting the right aids and adaptations.

Then together, whatever the pressing issues are we get it sorted and we don't stop till we do. The beginning of our journey

## Stage 2 : Partnership

*"When we love and respect people, revealing to them their value, they can begin to come out from behind the walls that protect them."* – Jean Vanier

Yes it's that word respect again, in case you haven't already guessed that is the big secret of our success and we really need everyone to get on board with this.

Imagine that you are a parent carer, and over the last 40 or even 50 years you have had more than your fair share of encounters with the "real experts".

Don't get us wrong we need those experts and many of them have worked miracles for us. Sadly all too often that has also meant being patronised, scolded, yes really! Made to justify our existence, be criticised and often have to repeat our stories literally hundreds of times.

No surprise then that the parents we meet are fiercely independent and often reluctant to admit if they are struggling or vulnerable.

Often they are uncomfortable talking about or even facing some of their fears for the future. If they can't manage what happens? Who will look after their child when they are gone?

So here we are at the second stage of our journey, by now we have earned their respect and take our word for it if we respected them before we are inspired by them now.

Then and only then when we have a real relationship with them do people open up and that's when the real partnership begins based on mutual trust.



# THE REST

In case you haven't already guessed this is the bit about giving people the information they need, the right support and tackling isolation. Now we get really busy!

## Information & Advice

*"If you have knowledge let others light their candles at it" - Margaret Fuller*

We hold regular information events for parents on topics they have asked about and here we would like to sincerely thank the experts and professionals who have come in and shared what they know.

*"You seem to actually be doing and saying the things we are doing and saying, it has all been very interesting and your information will be very helpful to us"*

Feedback from a parent who came to one of our information events.



## Carers Lunches

We hold carers lunches - which is an opportunity for parents to meet each other when as well as sharing their ideas and top tips they can also offer mutual support and make new friends.

*I am very happy I came to Talbot House I can say this, House of Hope, where everything can happen to the best...  
.I love everybody in this house.*

Bridget Jakobsen - Note Bridget is now one of our amazing volunteers.





## TLC & Company

*"The person who tries to live alone will not succeed as a human being. His heart withers if it does not answer another heart. His mind shrinks away if he hears only the echoes of his own thoughts and finds no other inspiration." – Pearl S Buck*

Sometimes if we can get funding we even have the odd "jolly" and take some parents away for a subsidised weekend. We also offer an at home pampering service for elderly and housebound parents. Like our parents though we are never off duty and these trips and pampering visits actually serve a very serious purpose.

Time away = Time to talk and often this is where we find out about the really important stuff.

It also makes a huge difference to isolated – often lonely parents.

# Advocacy

“Never be afraid to raise your voice for honesty and truth and compassion against injustice and lying and greed. If people all over the world ... would do this, it would change the earth.” – William Faulkner

We could write a book about this it is a huge part of what we do and ranges from attending appointments and writing letters all the way through to formal appeals.

We want you to enjoy our report but we are not going to pull any punches either so here is an example which even with our support took 12 months to finally sort out.

One of our parents Neil, an 87 year old widower who cares for his daughter at home applied for money from the Independent Living Fund on her behalf and she was granted this and in receipt for 2 years. This made it possible for her to continue to live at home.

She was then re-assessed – the benefit was cut immediately and he received a letter demanding £40,000 repayment.

## SOCIAL JUSTICE? CIVIL SOCIETY?

Imagine that was you – we sorted it but **IT SHOULD NEVER HAVE HAPPENED!**

# SPREADING THE WORD

Getting the message across – we seriously don't know how they find the time but Fran, Bernie and the volunteers especially Bev and Helen also get out there and let people know we are here. We hope this report will do that some more.





# PEER SUPPORT

We have some amazing volunteers who do a whole range of things from being a listening ear right the way through to supporting individual parents. They really do go the extra mile! It is inspiring how people who first came to Talbot House for help then go on to give back in a big way. Just one example is Bev:

Bev has a son Nathan who has severe learning disabilities, a growth disorder and epilepsy – he has a high risk of status epilepticus. Bev heard about TH from a group at school and contacted us after her own mother had a heart attack. Bev had to move in with her mum and continue to look after her son so the pressure was really on, but as she said very eloquently when describing the advice given to her when he was born, *“I didn’t have Nathan to give him away!”*

Talbot House was there for Bev when she needed it and Bev is now a highly valued member of the team and over the years has been a real presence. She set up a play scheme, was involved in making a film for “All North”, has raised funds for trips helped to get information out to parents, got “in-kind” donations for TH, has been a lead in developing the person centred profiles and is now a key volunteer with the Thrive scheme taking on cases with minimum management support.

Bev did have something to say about the impact Talbot House has had on her life and puts it as follows:

*“Nobody makes any judgements about you; it has given me the confidence so that I can help other parents. In TH everyone is equal.”*





# Parent Stories



# A Parent Carers Story – Carrying on regardless

Isabel is 84 years old and is mum and carer to William aged 63 who has learning disabilities. Isabel was referred to us by staff at the day centre that William attends as they had concerns about the care services in place for William when at home.

We visited Isabel at home and were horrified to hear that the carers who came to her house to support William were not only coming and going as they pleased but alarmingly she felt intimidated by certain individuals who were calling at 6.00am and 7.00am instead of 9.00am. When she challenged them about this as it was far too early she was met with aggression, and the paid carer just pushed past her to get in.

Clearly this is totally unacceptable and we were disgusted that a lady of this age and her extremely vulnerable son were being treated so badly. Fortunately Isabel has a long standing family friend and regular visitor who calls most days to make sure they are both ok.

Isabel wondered if it was possible to transfer the care package for her son to employ this person whom they both trusted with his care.

## What We Did

We immediately contacted social services and informed them of the terrible behaviour the paid carers were displaying towards Isabel and William, and asked for an urgent reassessment of need for both and on Isabel's behalf stopped the agency with immediate effect. In the interim the family friend took over on a voluntary basis to support William with his needs.

## The Outcome

The reassessments were carried out immediately and the family friend is now employed as a personal assistant to William and keeps an eye on Isabel as they are both so vulnerable. Social services have assured us that they will deal with the agency, so that this treatment will not be meted out to other vulnerable families.

Unfortunately Isabel had a bad fall and she contacted us again for help. We went to visit her with a Social Worker and arranged for William's support package to be greatly increased straightaway and to have respite in place. We also made contact with the neighbourhood PCSO and asked him to keep an eye on them both as they are now more vulnerable than ever.

We are happy to say that Isabel has recovered and has attended Carers Lunches and Coffee mornings. The increased budget is still active and we are hopeful that will be the case in future.

This has allowed Isabel and William to continue to live together as they would wish.

Names in this story have been changed

# A Parent Carers Story – Letting Go

Sometimes we support parents to see their child move on to a new home, never an easy decision but sometimes necessary.

Mary is the mum of Mark who has severe learning disabilities and physical health problems. She has had a long standing relationship with Talbot House but only contacts us when she really needs to. Helen who is a Thrive volunteer met with Mary who confided in her that she was struggling to look after Mark on her own after her husband died.

This was a very tough time for Mary given that her beloved husband had recently passed away and she felt that she was letting Mark down by looking towards alternative care away from her.

## What We Did

Helen supported Mary from start to finish in going to view residential places for Mark that would suit his complex needs. We liaised with Social Services in regard to funding and various meetings were held here at Talbot House thus enabling Mary to feel more comfortable and reassured that she was not facing this difficult decision alone.

## The Outcome

A budget was agreed and a residential home for Mark was found where he is extremely happy and well looked after.

Mary can now rest and begin the grieving process for her husband as this was interrupted by the overwhelming emotion and heartbreak at having to admit she could not look after Mark in the way he was used to.

We continue to support Mary and she has become a regular visitor to Talbot House.



Names in this story have been changed

# A Parent Carers Story – Update on Neil and Diane

Earlier in this report we mentioned Neil and his daughter Diane who had to fight a demand for him to re-pay £40,000 after she was re-assessed. We continue to support Neil but even with our input life gets harder for this amazing man.

Both he and his daughter have mobility problems, Neil has had 2 knee operations and Diane has recently become very ill. Neither of them can climb the stairs anymore and Diane is scared to be alone at night since her illness. As a result both of them are now sleeping in the lounge.

In March this year (2016) Diane's care needs were again re-assessed and yet despite the obvious decline in the health of both of them they have been informed that their budget will be significantly cut.

**We have of course lodged an appeal and are awaiting the outcome.**

Neil has worked hard all his life and owns the house in which they live but the area where the house is has deteriorated to a degree that makes it impossible to sell.

Ideally they need to move into a bungalow but selling the house will take a long time given the area.

## What We Did

We have registered Neil and Diane on the Manchester City Council Home finder web site and organised a medical assessment for them both, this needed to be a priority as it would give them further points on the social housing list.

## The Outcome

This medical assessment has now been completed and their application is now open to bidding for homes, unfortunately Bungalows are few and far between so we monitor the Home finder website on a weekly basis on the family's behalf. We are hopeful that we can secure a suitable home as soon as possible. We are awaiting the results of the appeal against cuts to their support package.



# A Parent Carers Story – When a Parent Dies

Karen and her husband Dave looked after their nephew Ian and also Ian's mum and his other brother all of whom had learning disabilities. Ian's brother passed away suddenly some years ago and his Mum, Karen's sister died more recently after a serious illness. We first met them when Karen requested support with Ian's reassessment of need. A package of care was secured for Ian that would enable him to continue to live at home.

Sadly Karen was diagnosed with cancer and after a short illness died which left Dave as the sole carer. A few months later Dave contacted us to say he was struggling to cope alone. We continued to visit Dave and secured a place for Ian 3 days a week and for a time it did give Dave some respite as he was almost a prisoner in his own home. Unfortunately Ian could not sustain the placement and after a few weeks was back home full time.

Ultimately Dave was unable to cope at all and the care broke down completely. People need to understand the full impact of this, not just on Ian but also on Dave who had promised his wife that he would look after Ian when she was gone.

Without Dave it became an emergency. We spoke with Social Services staff who had organised emergency respite but Ian was refusing to leave the house. Again please think about how terrifying this was for Ian, we rushed down and found Ian cowering in his bedroom. After a long time with someone he knew beside him he calmed down and agreed to leave.

Ian is gradually settling in to his new life and we keep in touch with Dave who is still struggling to come to terms not only with the loss of his wife but also haunted by not being able to keep his promise.

## A Hugely Important Lesson For Us All

It would be very easy to blame Dave or Social Services for this sad story but the truth is much more complicated. In reality it is not uncommon for care to breakdown when a parent dies. Often a sibling or partner has sincerely promised that they will carry on alone but it isn't always possible. We are talking with our parents about that most difficult subject, "what happens when I am gone?" It is not an easy subject to talk about and there are no fairy tale solutions.

It is urgent that we find these hidden parents and that government invest real resources in supporting them now so that we are able to respond with compassion and respect and meet the needs of the parents who continue to do such an amazing job.

We owe it to them as well to make every effort to find out what their wishes are for their child when they are gone and as a society to be prepared for that eventually so that we can have fewer emergencies like this.

Names in this story have been changed

# ARE WE VALUE FOR MONEY?

## You better believe it!

We receive £25,000 per year from the Tudor Trust towards the costs of the project and the rest we make up from donations and small grant applications for the add ons like trips away.

In total the project costs around £29,000 per year to run but thanks to the incredible dedication of Fran and her volunteers we make that money go a very very long way.

In just under 18 months we have supported over 48 families, often with quite complex needs and situations. In addition to this case work we have also:

- Held 6 information events attended by over 250 parents in total on subjects such as, legal matters, shared lives, safeguarding, community safety, one page profiles, staying healthy.
- Provided an at home pampering service to housebound parents.
- Monthly free legal advice surgeries
- Held 7 Carers Lunches each attended by over 50 people.
- Compiled a resource pack full of useful information for parents and volunteers.
- Been out and about promoting the service to parents and professionals.
- Supported people with Hospital visits and kept parents informed through mail-outs and phone calls.
- Paid for bereavement counselling

Made a million cups of tea, laughed, cried and listened.



## FRAN GETS THE LAST WORD

When they told me I could have the last word I struggled, there is so much I have to say but we followed our own rules and I talked and someone else listened. Together we managed so here it is.

I absolutely love my job, I feel privileged to do it and I am inspired and humbled on a daily basis by the people I meet. In fact my last words come from a parent whose response to an awful lack of compassion left me speechless, humble and more determined than ever to do my job.

Jayne who is in her 90's and lives at home with her disabled daughter went for her annual health check. She had the misfortune to see a locum who had never met her before but felt it was okay to tell her that she and her daughter should be in a home as they couldn't possibly be capable to manage - what if one of them died in the night!

### Well here is what she said:

*"Well Fran you can imagine how scared we were after that. We never think about dying normally. Anyway we talked about it and now every night we get into bed together and wrap our arms round each other. That way we know if one of us dies they won't be alone."*

# So all I want to say or rather shout as loud as possible is:

TO ALL YOU PARENT CARERS OUT THERE **YOU ARE AMAZING** AND DESERVE ALL OF OUR RESPECT AND ADMIRATION!

TO ALL YOU POLITICIANS – **ARE YOU REALLY LISTENING???**

TO PLANNERS AND COMMISSIONERS – WE KNOW YOU ARE STRUGGLING TO MAKE ENDS MEET WITH **CONSTANT CUTS TO PUBLIC SPENDING** BUT THIS MUST BE A PRIORITY FOR INVESTMENT NOT CUTBACKS.

TO THE READER – **SPEAK UP – NOTICE YOUR NEIGHBOURS – IMAGINE....**



# THANK YOU

First and foremost thanks to all the parents who let us share their journey.

We also want to recognise our own not so invisible hero Bernie Wood who at 76 is still running Talbot House, still doing an amazing job of looking after her own son Geoffrey and well if you ever need to be inspired just pop in for tea and meet her.

Our amazing Thrive volunteers of course who do so much when they could be sitting back and relaxing at home. Thank you to Deirdre, Denise, Bev and Helen.

If you work for health or social services, we know sometimes we can be at loggerheads with you. It is our job to fight for parents and we do that with no apologies but hey isn't it great when together we make a difference.

We would like to recognise Manchester Learning Disability Partnership Team based at Crescent Bank in Crumpsall, MacMillan Nurses, the District Nursing team Ann Fleming, Richard Long, and Cecilia Udu to name but a few social workers.

So to all those professionals, and there are many who do go the extra mile - THANKS

We also want to thank The Tudor Trust and our grant manager Joanna De Havilland, not just for providing the funding but also for taking a real interest in the project and responding quickly when we have needed to ask about anything.

Thanks to Trusha Valji from Touch Solicitors who provides the free legal surgeries.

Lisa and Viv who do so much more than just pampering.

Last but not least a huge thank you to Satish whose donation made it possible to double our printing budget for this report.

Also to STRESS FREE PRINT for doing such a fantastic job and also donating some of their time and expertise reducing the costs even more.

**And thank you for taking the time to read this.**

# If you have been inspired by this here is how you can help.

- 1.** When you see a person with a learning disability remember they have no less value than anyone else.
- 2.** Notice your neighbours – are they isolated – are they a parent carer – make contact – just say hello.
- 3.** Volunteer – not necessarily with us there are many organisations out there who need support.
- 4. Speak out** – Imagine you were a parent carer use your voice to make things change.
- 5. Donate** – Of course we need money and every little helps our details are on the back cover.





**This report is dedicated to the memory of Ann and Tommy Kelly  
two of our hidden heroes**

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**THRIVE**<sup>TM</sup>

Supporting Parent Carers Over 50

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