



**The King Henry VIII Endowed Trust,
Warwick.**



Who Cares We Care Evaluation Report

**Generously Funded by
King Henry VIII Endowed Trust
Warwick**

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Headline: Entrust Care Partnership's Programme *Who Cares We Care* records a 37% increase in participants' health and wellbeing following seven workshops.

Introduction

King Henry VIII Endowed Trust kindly awarded us a grant to host our seven-week programme entitled ***Who Cares We Care***.

Our Who Cares We Care programme of 'health hot slots' for parents and carers caring for a child or young person with a disability, residing in the CV34 district with each session focussed on carers expressed priorities of need in relation to keeping healthy and well.

Evidence of Need

Parents and carers naturally have a lifelong commitment to their sons or daughters which is likely to be practical, social and emotional, often continuing well beyond the usual societal pattern of independence. Although it is reported that there are high points and cherished experiences as with any family, it is widely acknowledged that these 'care givers' can become 'drained and running on empty'.

Warwickshire Observatory states that generally women were more likely to be unpaid carers than men; **58% of unpaid carers in Warwickshire were women** and 42% were men. This gender difference remains broadly similar irrespective of the number of hours of care undertaken each week. Overall, in Warwickshire, those **providing unpaid care** were more likely to describe their **general health as 'not good'**; 25% of those providing some unpaid care each week described their **health as 'not good'** compared with a lower rate of 17% among those who provided no care at all (Census 2011).

We have seen from research evidence and Entrust's own consultation that parents and carers can be particularly vulnerable to health and wellbeing problems including those associated with isolation and a feeling that 'it is only happening to me'.

Contact A Family Research (2011) The impact of isolation on families with disabled children across the UK reported that 65% of families who participated reported feeling isolated frequently or all of the time. Furthermore:

- **72%** experience mental ill health such as anxiety, depression or breakdown due to isolation
- Almost half (**49%**) have felt so unwell that they asked their GP for medication or have seen a counsellor
- **57%** say lack of support means they are isolated and not able to work as much as they would like
- 1 in 5 (**21%**) say that isolation has led to the breakup of their family life.

The Who Cares We Care programme was carefully prepared in seeking to address some of these identified needs and improve the health and wellbeing of those attending. This Evaluation Report details the programme itself, the content of the sessions offered, profiles the participants, shares the outcomes achieved and undertakes an analysis of the evidence presented by the completed wellbeing Questionnaires.

Who Cares We Care Programme

The programme was managed by Entrust Care Partnership Directors who secured the timetable, organised the venue, lunch, guest specialist presenters, marketed the programme, accepted and processed referrals, acknowledging places secured, facilitated and welcomed people from CV34 Warwick to each session to ensure smooth and well-prepared workshops.

Participants were encouraged to attend the whole programme although each individual Workshops could have been attended on a 'stand alone' basis. It was aimed solely at parents but for two particular sessions a person with a Learning Difficulty, living in the post code area, had requested a place and was welcomed by the Group.

Each session was held at St Michael's Church Centre, Church Lane, Budbrooke, Warwick CV35 8QL. Each individual session ran from 10am and finished at 12 noon followed by a one hour shared lunch. This enabled participants, facilitators and guests to continue engagement.


Tables were prepared beforehand by the facilitators and the flowers, refreshments and fruit were appreciated by those who attended.

The topics specifically selected to improve attendee's health and wellbeing included the following areas over a **seven week** period:

Who Cares We Care: Parental Workshops making you the 'centre of attention May - June 2018

Timetable

Date	Description	Guest Facilitator	Notes
Tuesday 1 st May 2018	Introduction to each other and the programme. My journey so far Health and Well Being with 24/7 care <ul style="list-style-type: none"> Building Emotional resilience 	Nilam Gill (Counsellor) runs a successful counselling practice Time for Hope and will be leading this session which will examine emotional resilience. She will be joined by Sarah Calvert.	<ul style="list-style-type: none"> What is Emotional Resilience How to develop Emotional Resilience Learn Coping Techniques Resilience as a way of life
Tuesday 8 th May	Health and Well Being with 24/7 care <ul style="list-style-type: none"> <i>Healthy Life Style Choices</i> 	Vanessa Aparicio-Hancox Nurse, lecturer & healthcare specialist. Founder of Family Landscapes	What constitutes a healthy life style, emotional & physical well-being, latest thinking and how can we maintain the right balance! <i>And in the Hampton Room first floor</i>

Date	Description	Guest Facilitator	Notes
	Practical calming techniques to use every day	Kathie Johnson, Entrust Care Partner and Colleagues	Kathie and her colleagues will share some very practical, quick and easy techniques which parents can use in their everyday life to relax and create moments of calm.
Tuesday 15 th May	Communication: Life Coaching <ul style="list-style-type: none"> <i>Empowerment Getting your voice heard</i> 	Clay Lowe, a leading coach and trainer based in the UK. His main passion is the pursuit of excellence	Understanding how to get your voice heard with organisations, professionals and daily interactions in an assertive but non-confrontational way.
Tuesday 22 nd May	Health and Well Being with 24/7 care <ul style="list-style-type: none"> <i>Strategies to combat stress and its affects</i> 	Heather Stack, Founder of The Local Offer, a social enterprise increasing access to specialist support for parents & carers.	The workshop is called: A Little Workshop of Calm for Parents & Carers. Exploring emotional energy, personal stress triggers, action plans and Dream Boards.
Tuesday 5 th June	<i>Mindfulness & meditation</i> <i>Reflexology, Reiki and Massage</i> <i>Wild Things and Gold Rings</i>	Corrine Armsden, Holistic Therapist runs a successful business in Wolsten namely 'Stop & Smell the Roses'. Karen Argent, former Senior Lecturer in Early Childhood Education and Care, Newman University, Birmingham. Founder of the Letterpress Project.	Corrine will be with us for three hours and following the presentation will be offering individual & discrete taster Massage, Reiki or Reflexology for individuals. Karen will then introduce us to the world of children's literature. Counselling Service, 10 – 1pm individual slots available to book with Nilam Gill <i>Hampton Room plus Warwick Counselling Room 1st Floor</i>
Tuesday 12 th June	Understanding sleep patterns and living with interrupted nights	Vanessa Aparicio-Hancox Nurse, lecturer & healthcare specialist. Founder of Family Landscapes	Effects of not sleeping well and how to combat fatigue, helpful strategies to cope with lack of sleep <i>Hampton Room</i> Counselling Service, 10 – 1pm individual slots available to book with Nilam Gill
Tuesday 19 th June	Making Images: art as play, self-expression and healing. <i>Strictly come dancing</i>	Jane Scheuer, State Registered Art Therapist Miss Laura Love Ballet Dance Company	Introduction to the idea of art for self-expression, and the opportunity to play with art materials. No art skills needed. <i>In the Hampton Room first floor a dance class 45 minutes from 11am.</i> 

Entrust Care Partnership were able to add value to the programme by offering individuals alternative therapy treatments provided by Volunteers these additional sessions were offered alongside the main topic of debate.

The provision of one to one Counselling enabled 8 participants to have individually tailored support.

The shared lunch enabling the discussions, friendships and mutual support to develop, and has left a legacy after the programme finished as participants agreed to maintain their contact with one another, forming a What's App Group. One of the parents has already facilitated a reunion for participants at her home after the programme concluded, with another session arranged for the attendees in September.

A total of **21 hours of direct intervention** was provided over the duration of the programme. There was also continuing contact in between sessions, mostly via email and the telephone.

The programme was promoted through traditional distribution of leaflets and the use of Social Media. We engaged with Warwickshire County Council's and Health's range of Disability Services, Warwickshire Parent and Carer Forum and our own Warwick based families this led to a total of **16** applicants, including the adult with Learning Difficulties.

Each participant completed an application form giving basic details of themselves and the disabled child, young person they cared for, a copy of which is located in the Appendices.

Entrust Care Partnership is 'pan disability' and we support any child or young person and their family irrespective of the nature of their disability. Given below are details of the family demographics as far as they are known to us and described by the participants.

Participants Profile

It is noted that some of the parent's children have multiple challenges.

Disability of the child or young person as described by parent/carers

Autism spectrum disorder, nonverbal, sensory processing disorder, Sleep & incontinence difficulties

Severe, Learning, Speech & Language Delay

Downs Syndrome

ASD and Social Anxiety

1p36 Deletion Syndrome (A genetic condition that results in a variety of health problems and means that he can't walk or talk)

Autism

ASD

Down syndrome & autism, non-verbal.

Both are as yet undiagnosed but have hypotonia, hyper mobility of the joints, speech & language delay, Gastro-oesophageal reflux disease and global developmental delay

Aspergers with Anxiety

ASD and GAD

Autistic Spectrum Disorder, ADHD, OCD and sensory processing disorder

Global developmental delay, epilepsy, autism

Autism

Gender of participants and child/young person cared for

15 of the participants were female. 1 was male. One of these parents described herself as having Autism, the adult with a Learning Disability also had a diagnosis of Mosaic Down Syndrome.

Between them they were caring for 18 disabled children and young people, there were 11 boys and 7 were girls.

Age of child/young person cared for

The youngest child cared for was aged 3 years and the eldest 22 years.

This span of age ranges of the children added to the discussions and mutual support offered as past experiences and lessons learnt were frequently shared between participants.

The dedication and focussed commitment to care for their son or daughter was very evident and it was noted that all absences recorded for the workshops were all child/young person related.

Outcomes Achieved

Healthy Lifestyle

- The majority of participants indicated they were or were going to use strategies used within the programme – diet, exercise and methods of stress control
- Parents attending expressed an interest in joining a *Walk & Talk Group* organised by another parent which will increase levels of physical activity
- Greater understanding of the effects of sleep deprivation and how to ‘pay your sleep debt’ in order to function more effectively

Communication & self confidence

- Participants interest in the workshop session ‘getting your voice heard’ was high

- Techniques reportedly used within settings during the course of the programme for example child's Education, Health and Care Plan
- Strategies for delivering your message in a way which will be listened to were shared and put into practice
- Increase in understanding a responsibility for some 'my' time to be built into even the busiest day

Supportive Friendships

- Ongoing connections and mutual support arranged by parents/carers themselves
 - Participants shared telephone numbers and set up a What's App Group
- Mutually supportive comments and advice shared by those present throughout the programme
- Sessions gave time for reflection and a focus on care givers needs which were reported to be beneficial
 - Reduced isolation which is often a factor for this service user group

Improved mental health and well being

- 8 participated in the Counselling sessions which were offered and 1 has explored further sessions
- Strategies are reportedly being used on an ongoing basis for example the use of mindfulness
 - Improved health and wellbeing as per the results of the questionnaire
 - Increased strength and family resilience reported

Sustained pool of volunteers

- Entrust Care Partnership continues to recruit more volunteers on an ongoing basis
- Every person who attended who wanted alternative therapies had the opportunity to engage and receive treatment reporting verbally how useful the sessions were
- Volunteers added value to the programme and have a greater understanding of the issues faced by parents and carers

Analysis of Evidence

1. Methodology

The pre and post Questionnaire given to participants is located in the Appendices. This tool uses WEMWBS, the Warwick-Edinburgh Mental Well-being Scale, to measure a person's mental well being.

It was developed by researchers at Warwick and Edinburgh Universities in 2007. The tool is reportedly often used by scientists and psychologists to measure wellbeing which means 'feeling good and functioning well'.

The Questionnaire was given to participants at the first workshop and again at the final workshop, in the event of any parental absences it was emailed to participants for completion.

One of the participants had only attended for four sessions but still completed the Questionnaire.

The **scores** are interpreted by WEMWBS as follows and it should be noted that generally most people have a score between 41 and 59.

0 - 32 points indicates a wellbeing which is very low. With this score it suggests that the person may wish to begin talking to a friend or health professional in order to address the feelings.

32- 40 points indicate a wellbeing score which is below average and the suggestion here is to take action to improve mental health and wellbeing.

40 - 59 points indicates that the wellbeing score is average but still can be improved upon.

59 – 70 points indicates good news that the wellbeing score is above average.

The five evidence-based steps they advise for everyone in order to improve mental wellbeing are to:

- Get Active
- Connect with others
- Keep learning
- Be aware of yourself and the world
- Give to others

The scoring process was not shared with participants and no feedback was given as part of the Workshops, some completed questionnaires were anonymous, others were named.

2. Questionnaire Results

There were 16 participants, as already noted, however we only have reliable and complete data from 14 participants and therefore the following results are based on these **14 sets of 2 questionnaires, one before intervention and one completed post intervention.**

Prior to the commencement of the programme and based on the above scoring method, as described, **three of the participants had a very low wellbeing score** i.e. 0 - 32. Additionally, **three** of the fourteen participants' questionnaires indicated that there was only one point which placed them in the next category, i.e. a score of 33. **None** of the participants had a wellbeing score which **was above average.**

At the commencement of the Workshops, **8** participants scores were identified as being between **32- 40** which placed their wellbeing **below the average** in relation to others in the population. This score suggests that there is a need to take action to improve mental health and wellbeing.

3 participants registered a score in the next category which placed them on the **average** scale for wellbeing with scores of 41 and 50 respectively. WEMWBS suggests that this score can be improved upon.

We anticipated that there would be some positive improvement in the scores but the results exceeded our expectations.

There was significant improvement in **ALL** participants' wellbeing following workshop intervention and when taken as an average the **difference is measured as a 37% improvement** in the participant's wellbeing.

Further investigation of some participants individual comparative pre and post questionnaires reveals that from (Candidate JW) '**rarely feeling close to other people**' beforehand to '**always feeling close to other people**' and also worthy of note is a move from '**rarely feeling confident**' to '**always feeling confident**'. WEMWBS highlight the evidence-based steps to improve mental wellbeing one of which is 'keep learning' a number of new concepts, ideas and strategies were introduced to those attending the workshops and it can be assumed that this improvement can be seen to correlate with this.

Another Candidate (JL) is also illustrative of significant improvement in wellbeing linked to 'Connect with others' on the five evidence based steps from only '**rarely feeling cheerful**' before the workshops '**to always feeling cheerful**'. From a position of '**rarely feeling good about myself**' to '**always feeling good about myself**' demonstrates how putting carers needs first, making them the centre of attention albeit for a short time helps in avoiding mental health problems and helps carers feel good and therefore function well.

A further candidate (CJ) pre-questionnaire reported '**rarely being interested in new things**' to '**always being interested in new things**' post questionnaire.

In calculating the average for the group pre-questionnaire, the score is **35.8% and this score falls within the below average mark on the wellbeing scale**. Using the same average calculation for the group post questionnaire the score is **49%** this score falls within the **average wellbeing range on the wellbeing scale**.

In summary before the workshops the overwhelming majority of participants scored below average on the wellbeing scale, but post programme **everybody** attending had improved their wellbeing and had moved to having at least an average wellbeing score, with **4** participants scoring above the average.

Service User Satisfaction: Quotes from participants

During the workshops interaction, engagement and participation was very high. All participants were complimentary about the programme, the guest facilitators and the content with no negative comments or suggestions for improvements. Some of the 'thank you's' from the group are listed:

Thank you so much for bringing this group together. I've made some great friends and finally feel like I have some support. It's just been unbelievable

Thank you, it has helped so much, love and hugs

Best course ever. Brilliant speakers, fab venue, great food, just class

Thanks so much it's been brilliant

This is the best thing I've had for me in years! Thank you so much. With much love

Thank you so much for everything this experience has been invaluable to me. Enjoyed your company and meeting everyone so much

You are an amazing special woman. The world needs more of you. Thank you

Thank you so much

Thank you for a wonderful few weeks, keep doing what you do! I have had a great time and met great people

Thank you for everything, especially emailing me about this course

Dearest - you truly are an earth angel! Even when I've seemed less than grateful, you've not given up on me and always have a smile that feels like its just for me. Thank you so much



Coaching



Taking care of yourself

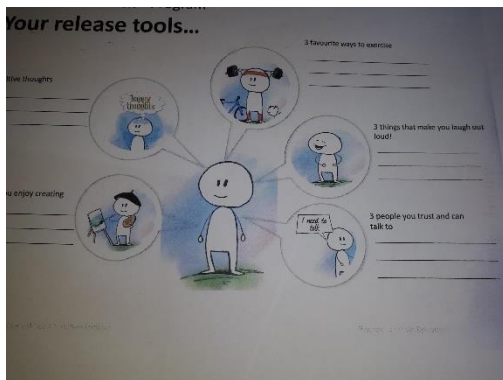


Art Therapy

Life Coaching Session - finding your voice



Tools and affirmations to help wellbeing



Finance The total grant allocation was **£6,029**. The programme remained within the budget and the table below reconciles the allocation with actual spend giving a brief description of variations.

Function	Description	Total Cost of Service £	Requested from King Henry VIII Trust £	Notes on Variations
Facilitation	7 direct contact @ 3hrs, plus 3 non-direct for preparation & evaluation	1,800	1,800	None
Visiting health and other professional presenters	Specialised guest presenters as per the timetable	1,911	1,891	None
Counsellor	1/1 individual sessions	400	420	Additional half an hour provided
Refreshments	Shared lunch@ £6 per head for all participants & presenters	588	728.00	Thomas Oken & purchased milk & coffee etc
Venue Hire	4 hours includes setting up and clearing away	600	436.50	Discounted rate
Administration and Payroll	Outsourcing payroll for project	150	150	None
Travel: volunteer, staff & presenters	Travel will be paid within local area only. Plus other expenses	210	172	Some claims not submitted
Promotional Leaflets	Printed Leaflets for distribution	70	78	Price variation
Resources	Includes all paperwork, folders & programmes for each participant	300	353	Price variations on goods/pens/wallets
Disclosure & Barring Service Checks	£15 per volunteer & £60 per paid staff. Assuming 2 staff plus 2/3 volunteers offering therapeutic intervention.	165	0	None
General Stationery	General supplies, care records, referral forms etc	100	0	None
Management, Governance & Supervision	Management & Governance and general administration throughout project @ £30 per hour (average) for 1-hour x 7 sessions	420	0	None
Total		6,714	6,029	

Summary

The **Who Cares – We Care** programme, a series of health slots to support parents and carers of disabled children, young people and adults in CV34, has been very effective in improving participant's mental health and wellbeing. The use of the well-established and respected questionnaire WEMWBS, before and after the programme demonstrated a **37% improvement in the wellbeing scores of participants**.

There are of course other variables which could have contributed to this achievement and it is a small number, however this is the third programme we have run and the scores have been consistently good.

These positive improvements can be seen as a preventative intervention as participants had moved from **below average scores to average wellbeing**, with **four** reaching scores which equated to **above average** wellbeing when compared with the population.

If their very low feeling of wellbeing had continued on an ongoing basis this may have had a cumulative effect and been detrimental to the health of the participants who at some stage may have had to seek professional psychological and medical intervention.

The cost of the total programme over the seven-week period seems to represent good value for money @ £53 for a three-hour session (including the shared lunch) based on 16 participants in relation to the positive outcomes achieved.

The strategies offered and taught were of little or no cost if continued at home, for example once understood the concept, philosophy and methodology mindfulness is a matter of time rather than funding.

The participants of their own volition made arrangements to maintain contact for mutual support thus reducing isolation. Their What's App Group (I have the privilege to be included) is frequently in use and parents & carers are busy sharing news about their Child's Education, Health & Care Plans, Child & Adolescent Mental Health, Summer Activities and support following a recent Bereavement. There have been some very powerful exchanges and a great deal of mutual support. The Arts Therapy Session has resulted in one of the parents signing up for a twenty-week Art Therapy course in September. Another parent has already begun Volunteering for us with another giving it consideration.

This programme's efficacy in alleviating stress and increasing wellbeing appears proven for parents and carers of disabled children

We take this opportunity to thank the following people for making this programme both successful and effective. Thank you:

First and foremost, King Henry VIII Endowed Trust for their generous funding

All parents and carers who attended

Kathie Johnson: Entrust Care Partner (Volunteer)

Kiran: Entrust Care Partner (Volunteer)

Catherine: Entrust Care Partner (Volunteer)

Clay Lowe: Life Coach and Trainer

Vanessa Aparicio-Hancox : CEO Family Landscapes

Heather Stack: Director & CEO The Local Offer

Corrine Armsden : Stop and Smell the Roses

Karen Argent: Joint Director, The Letter Press Project

Nilam Gill: Founder Time 4 Hope Counselling Service

Jane Scheuer: State Registered Art Therapist

Miss Laura: Love Ballet Dance Company

Carole Weaver: Director, Entrust Care Partnership

Jess: Oken Tea Rooms, Warwick

St Michael's Church Centre, Budbrooke, Warwick

King Henry V111 Endowed Trust – thank you again for funding the programme

Appendices



Who Cares – We Care

Entrust Care Partnership are hosting a series of informal **‘health hot slots’** for parents and carers of disabled children, young people or adults. Meet others, make friends, share experiences and lunch together, be the centre of attention for a change. Please apply below:

Your Name:	Postal Address CV34 :
Email	Telephone
Details of the person you care for: your child/young person/adult’s name	Date of Birth if a child or young person
Nature of child/young person or adults disability	Any particular Dietary requirements? We will try to accommodate these if possible
Particular Topics you are interested in	Other Information you want to share

It is important that you try to attend all 7 workshops. We may visit you at home or a convenient other location.

In applying to attend please note that **you are agreeing to complete 2 brief questionnaires** one before the workshops commence and one after.

This information will be confidential and anonymous but as the programme is funded by King Henry V11 Endowed Trust we are required by them to demonstrate that the workshops have been effective. Please return completed referral form to lynnebarton@btinternet.com I will contact you directly to confirm your place. Many thanks for your interest any questions email or telephone 07712326273

Instructions: Please tick the box that most accurately represents how you feel about the following statements:		NEVER	RARELY	SOMETIMES	OFTEN	ALWAYS
		1	2	3	4	5
I've been feeling optimistic about the future						
I've been feeling useful						
I've been feeling relaxed						
I've been feeling interested in other people						
I've had energy to spare						
I've been dealing with problems well						
I've been thinking clearly						
I've been feeling good about myself						
I've been feeling close to other people						
I've been feeling confident						
I've been able to make up my own mind about things						
I've been feeling loved						
I've been interested in new things						
I've been feeling cheerful						
Score:						
					Total:	

This Questionnaire is the Warwick - Edinburgh Mental Well-Being Scale and is used to measure your mental wellbeing (WEMWBS)