Public Document Pack

Scrutiny Inquiry Panel - Carer Friendly Southampton

Thursday, 8th October, 2020
at 5.30 pm

PLEASE NOTE TIME OF MEETING

Virtual Meeting

This meeting is open to the public

Members

Councillor Coombs
Councillor McEwing
Councillor Prior
Councillor Savage
Councillor White
Councillor Windle
Councillor B Harris

Contacts
Mark Pirnie - Scrutiny Manager 023 8083 3886

ADDITIONAL INFORMATION AND PRESENTATIONS

8 **CARER FRIENDLY SOUTHAMPTON - INTRODUCTION, CONTEXT AND BACKGROUND** (Pages 1 - 112)

Listed presentations from the evenings meeting

Unpaid carers:

Who, how many and differences during COVID-19

Emily Holzhausen OBE
Director of Policy, Carers UK

Emily.Holzhausen@carersuk.org

7 October 2020

Who do you have in your mind as a carer?

Young carers image from Signal4carers

Other images of Carers UK members. Copyright Carers UK

Largest part of the care system:

- 6.5 million or 13.6 million?
- Additional 4.5 million since COVID-19
- Value of support: £132 billion
- 58% women, 42% men, but women do more
- Peak age, 45-54, but can be any age
- 50:50 chance of providing care by 50, women 47, men 56
- Most don't call themselves carers

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carersUK

Overview:

- Majority of carers working age
- Growing number of much older carers
- Caring at a distance can be more stressful
- 1 in 4 of your workers juggling work and care
- 2.6 million given up work to care
- More likely to be under-pensioned
- Carer’s Allowance is £67.25 per week
- Av. 2 years to recognise as carer
- Parents of disabled children worse off
- Breaks still remain high priority

@carersuk

Overview:

- Twice as likely to be in poor health
- GP Patient Survey – younger adult carers, BAME carers, key groups are worse off
- Hospital discharge is a critical point
- Emergencies on carers' minds – how are contingencies planned for?
- Systems, not just caring, can cause huge stress
- Lack of right information and involvement at right time makes caring harder and makes people poorer.

Overview: Young carers

- Between 170,000 and 800,000?
- Developmental challenges, less likely to earn more
- Educational challenges 1 in 20 miss school
- 39% said no one at school knew
- Mixed experience of COVID-19
  - More people around at home is good
  - More people around at home is worse
  - Reports by Children's Society and Carers Trust

carersUK

Common goals:

Identified, but not "outed" e.g. young carers
Valued, including knowledge and opinion
Involved
Choice
Feeling in control
Financially better off
Being knowledgeable
Being linked to friends/society (not lonely)
Being able to continue working/return to work
Time to yourself and life outside caring
Positive health and wellbeing
Services and support that fit around people
Equality and society respect

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The law in relation to carers:

Care Act 2014:

- Duty to provide information and advice
- Duty to identify and assess on appearance of need
- Duty to provide services following eligible need
- Prevention duties – prevent, reduce and delay needs

Joint NHS and solely NHS duties:

- Joint ASC and health duties to promote wellbeing
- NHS duty to cooperate with LAs
- NHS responsibilities at hospital discharge
- CHC funding and assessments for breaks (NHS responsibility)
- Forthcoming publication on NHS legal responsibilities towards carers

The law in relation to carers:

Young carers and parent carers

- To young carers – ASC responsibilities to identify and support
- Children Act 1989/Children and Families Act 2014
- Parent carers – transition but also multiple carers/disabilities

Overarching

- Equality Act 2010 – discrimination by association
- Human Rights Act

As an employer:

- Equality Act 2010
- Right to request flexible working
- Right to emergency time off for dependents

Key results during COVID-19:

Carers UK – Caring Behind Closed Doors

- 70% doing more care, across all domains. Some doing less due to social distancing (9%).
- 18% unable to manage (1 in 5 caring 50 hrs +)
- 55% concerned about coming weeks and worried about burnout

Reasons for rise (can overlap):

- 35% withdrawal or closure of services
- 22% cancelled own care
- 10% care workers providing less personal care
- Disabled/older people’s needs have increased

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Where next?

Improved recognition – COVID-19

- Opportunity
- Carer friendly work e.g. Carer Passport

Work strategies locally:

- Low cost, supports own staff as well as local residents
- Employers for Carers
- Carer Confident – benchmarking for
- COVID flexibility employers more open
- Carer's Leave – manifesto commitment

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Where next?

Joint work with health

- GP identification schemes/Carers Prescription
- Quality Markers opportunity

Supporting young carers and young adult carers

- Support groups remain critical
- Identification and support through schools
- Memorandum of Understanding ASC/CS
- No Wrong Door
- Baseline numbers – how many?

Where next?

Carers' learning and development:

- Offering a suite of different learning
- Peer learning
- Online e-learning – bite sized, longer, digital badging

Personalisation

Carer ID recognition/Carers Passports

Where next?

Go digital, but offer blended approaches:

Digital is preferred by some

Digital more accessible for some

Can provide a universal offer to everyone e.g elearning

Blended approach works best – offer face-to-face/telephone, etc. as well as digital

Carer Involvement

Capacity building

Leading local services as volunteers

Other opportunities e.g. micro-employment

Contact

Emily Holzhausen:
Emily Holzhausen@carersuk.org

www.carersuk.org

www.Employersforcarers.org

@carersuk

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Agenda Item 8
Appendix 2

Carer Friendly Southampton Scrutiny Inquiry

Adrian Littlemore
Senior Commissioner

Kirsten Killander
Service Development Officer

Integrated Commissioning Unit

Number of Carers in Southampton

	Southampton Expected Numbers (as 8% of Demographic Populations)	% of Carers from Expected Numbers	% of Carers from Known Number of Carers	Southampton Incidence Known
Young Carers <8 - 18	c. 2078	20%	15	420
Adult Carers	c. 32,000	7.6%	85	4,068 2,428 in contact with service within past 2 years
Total in contact with CiS & No Limits (last 2 years_			2,848	
Of which there are:				
Parent Carers			5	153
Female			61	1,744
Male			24	679
Unknown Gender			15	425
BAME			15	438

Ethnicity of Carers

	Number Known	% of Southampton Population	% of Known Carers
British White	2,051	0.8	72
Arab	11	0.004	0.5
Asian/Asian British	256	0.1	9
Black British	42	0.02	1.5
Eastern European	82	0.03	3
Mixed/Multiple ethnicity	15	0.006	0.5
Other	39	0.01	1.5
Unknown	352	0.02	12

Age Profile

	Southampton Prevalence	Southampton known
Very Young Carers <8 years	0.04%	6
Young Carers 8-18 years	1%	414
Young Adult Carers 19-25 years	0.3%	80
Adult Carers 26 -64 years	1%	1405
Older Carers 65+	2%	626
Unknown age		320
Total	1% (8% expected)	2,837 (32,000 approximately expected)

2104 of Carers are identified as living with the person they care for.

Young Carers in Southampton

Cared For Need	Individuals cared for with:	420 % of carers
Physical Access & Mobility only	10	2.4%
Personal Carer	26	6.0%
Sensory Visual	0	0%
Sensory Hearing	5	1%
Dual Impairment	1	0.2%
Memory & Cognition	35	8.0%
Learning Disability & Autism	0	0%
Mental Health	43	10%
Substance Misuse	5	1%
Social Isolation	3	0.7%
Unknown	292	70%

Adult Carers in Southampton

Cared For Need	Individuals cared for with:	% of known Carers 2428
Physical Access & Mobility only	161	7.0%
Personal Carer	260	11%
Sensory Visual	10	0.4%
Sensory Hearing	2	0.08%
Dual Impairment	7	0.3%
Memory & Cognition	159	6.5%
Learning Disability & Autism	166	7.0%
Mental Health	367	15%
Substance Misuse	6	0.2%
Social Isolation	6	0.2%
Unknown	1284	53%

- 378 are caring for more then one person

SCC commissioned services for carers

Carers in Southampton

- ✓ Undertake Carers Assessments
  - Uploaded to PARIS IT system
- ✓ Provide advice, information, support
- ✓ Social Worker 1 day per week embedded from Adult Social Care

No Limits

Subcontract Young Carers Service

Range of Replacement Care for Adults

Direct Payments

Domiciliary care

Day Care

Overnight respite care

Respite over night breaks

	Number of night provided per year 2019/20	Approximate number of Carers Supported
Kentish Road	499 days	Adults with Learning Disability
Way a Head	592 days	Adults with a learning Disability
Rose Road	473 days	Adults with a Learning/Physical Disability
Holcroft House	801 days	Dementia
Oak Lodge Nursing Home	398 days	Dementia
Other in 48 services	2613 days	
Total	5779 days	

NHS organisations

- Carers Leads
  - University Hospitals Southampton FT
  - Solent NHS FT
  - Southern Health Trust
- Admiral Nursing –specialist dementia nurses supporting carers

Current Carers Strategy 2016-2020

priorities identified:

- ✓ carers identification and recognition
- ✓ information and advice
- ✓ collaborative and innovative support
- ✓ support in maintaining health, wellbeing and safety; and planned and unplanned breaks
- ✓ young carers protected and supported to learn and thrive.

4 themes that were acknowledged which ran through all priorities:

- identification and recognition
- need for education of carers, professionals, and community
- collaboration
- time for yourself

Learning from implementation

- ✓ Governance
- ✓ Data across organisations (recording and reporting)
- ✓ Focus on key enablers e.g. interoperable IT
- ✓ Changing practice and culture

Carers in Southampton

A free support service for adults caring for adults

Carers in Southampton is a project commissioned by Southampton City Council via local charity Southampton Mencap

CARERS IN SOUTHAMPTON
Helping unpaid carers

Phone: 023 8058 2387 Email: enquiries@carersinsouthampton.co.uk Website: www.carersinsouthampton.co.uk

Our team

Carers in Southampton	Role	Hours
Linda Lawless	Service Manager	30
Joe Jenness	Senior Coordinator	37.5
Balbir Kaur	Clerical Assistant	22.5
Sue Roberts	Carers Assessor	22.5
Mike Ktomi	Carers Assessor	22.5
Carol Carswell	Carers Assessment Reviewer	14
Helen Cox (joint with SCC)	Independence Advisor at SCC	7.5
Paul Daley/Rhona Hawkins	Specialist Carer Support Worker for Mental Health and Substance Misuse	22.5
Jagpal Karir	Specialist Carer Support Worker for BAME	14
Ashley Raynor	Specialist Carer Support Worker for Learning Disability, Physical Disability, Sensory Impairment and Older Adult	26
Pip Armitage	Communications Officer	18.5
Total		237.5

Our service offering

A free support service for adult carers offering

- Statutory carers assessments for adults caring for adults
- Guidance, signposting, referral
- Carer identity cards
- Emergency planning
- Social contact monthly and guest speakers
- Projects on healthy behaviours, mental health and bereavement support
- Recent covid-19 wellbeing support

Statutory carers assessments

- Carers in Southampton conducts statutory adult carers assessments on behalf of Southampton City Council
- Carers assessments evaluate needs and eligibility for support, services and a discretionary award
- Eligible adults must provide care and support to adults (18 years+) who are disabled, ill or elderly and resident in the local area served by Southampton City Council SO14-SO19 postcodes

Carers assessment outcomes

Support

- Staff with experience and knowledge of mental health, disability and BME provide guidance, signposting or referral to relevant support services
- Our support workers are not social workers, nor can they provide advice on benefits or legal matters
- All support is usually offered via phone and email unless there is an accessibility requirement

Services

- Carers cards providing identity and access to some discretionary discounts
- An emergency planning template with the option to ask SCC to hold it on record
- Website resources, information emails and a newsletter approximately three times a year
- A monthly carers lunch with invited guest speakers and helpdesk (currently suspended)

Awards

- A small discretionary personal budget for those providing significant levels of care (not means tested)
- Carers assessments **do not** produce an outcome of respite or paid carer services

How we work

- **Referrals or self-referral, currently**
  - By individuals 45%
  - By self-referral 30%
  - By external agencies 25%
- **Referral options**
  - Online at https://www.carersinsouthampton.co.uk/make-a-referral
  - Or use http://bit.ly/CiSRefer
  - Via email to referrals@carersinsouthampton.co.uk
  - Or phone to 023 8058 2387

How we work

- **Assessments and support are both delivered via phone and email**
- **Additional services**
  - Specific project work e.g. Male cancer direct mail information funded by Action Hampshire
  - Support groups for bereaved carers (currently delivered via Zoom)
  - KIT calls

Unpaid caring in Southampton

- Estimated 32,057* Southampton residents providing unpaid care and support
- They care for family member or friend with a range of disability, illness or age-related frailty including:
    - Mental illness, drug or alcohol dependency
    - Learning disability, autism, dementia, brain injury
    - Physical disability, sensory impairment
    - Long term health conditions e.g. lung/heart disease, kidney disease, rare conditions
- All carers are entitled to advice and information
- Some are eligible for additional support:
    - When a carer provides necessary care meeting one of the needs domains
    - Their caring role affects their physical and/or mental wellbeing

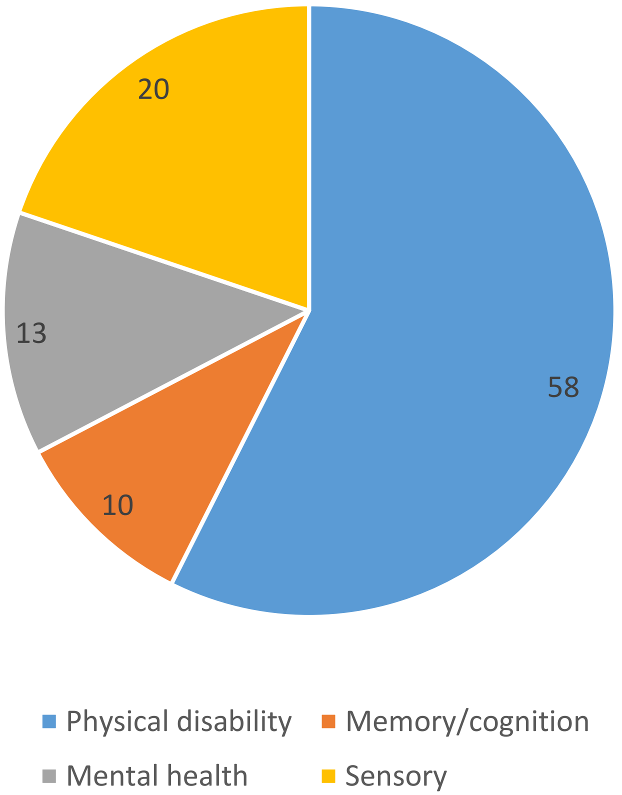
*Based on 12.5% of 256,459 est. pop. in Southampton Data Observatory

National vs local picture

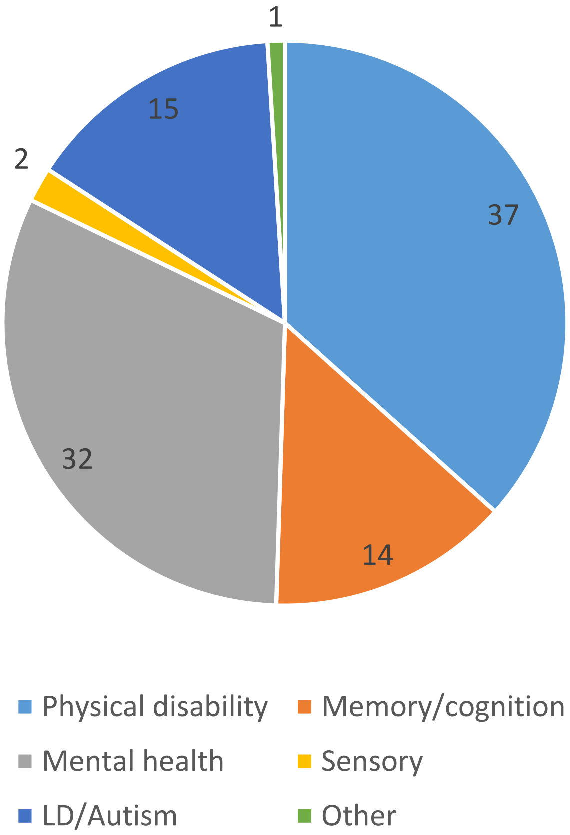
- Primary care reasons in CiS database **under**-represented in
  - Physical disability (37% CiS vs. 58% in Carers UK 2014 stats) but this year at 41%
  - Sensory disability (2% CiS vs. 20% in Carers UK 2014 stats)
  - Males (27% CiS vs. 42% in Carers UK 2014 stats)
- Primary care reasons in CiS database **over**-represented in
  - Mental health (32% CiS vs. 13% in Carers UK 2014 stats)
  - BAME (19% CiS vs. 9% in Carers UK 2014 stats)
- Areas to grow/increase referral:
  - Chronic co-morbidities
  - Kidney disease, sight/hearing loss and some cancers

Unpaid caring in Southampton

Primary care reason % UK



Primary care reason % local



Carers in Southampton database:
High % of mental health, LD/Autism
Low % of sensory and physical disability

But picture changing:
In 2020 new carer addition stats show
Physical disability now at 41%
Mental health 27%

Data source: Carers UK 2014 and CiS 2018/20

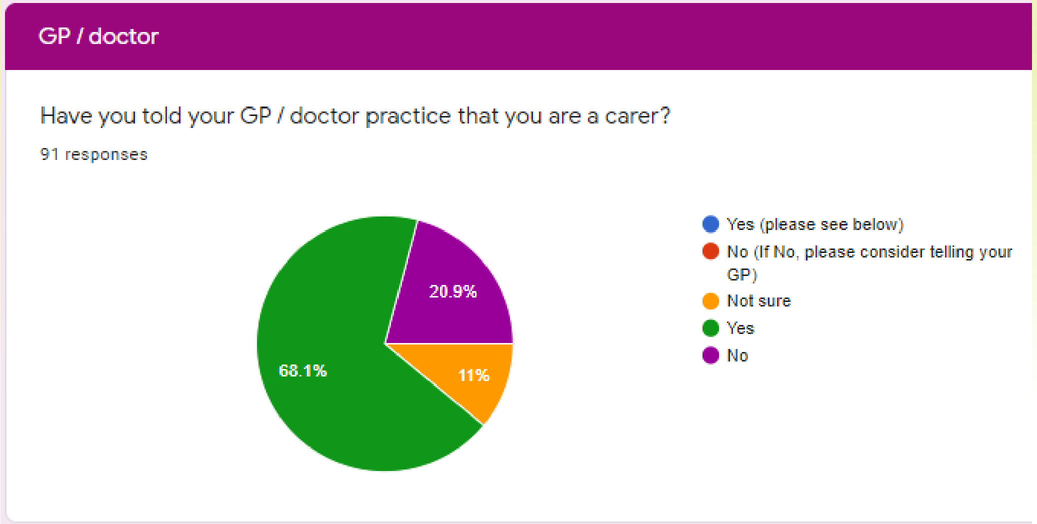
Service impact: Annual carers survey

Difficult to access most events due to caring responsibilities.

I love the newsletter and use it so much in supporting other families via various groups

You have all been very helpful, and the advice you have given and links very helpful. Everyone I have chatted with, over the phone or in person has been great, always polite and helpful. Nothing but praise for all of you. thank you .

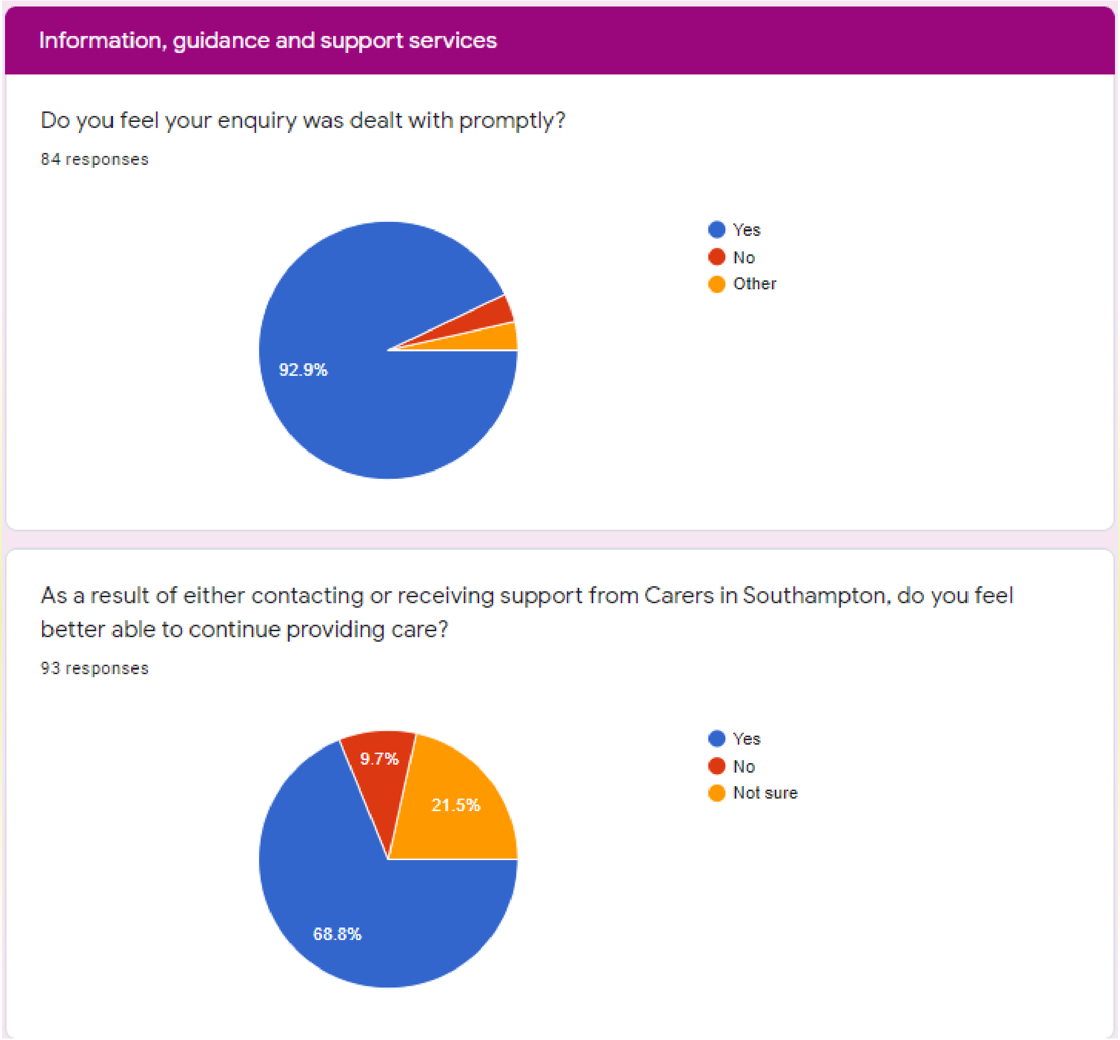
I think your service is good but ...my problem is not only care component but legal monitory issue which you don't deal with..



GP / doctor

Have you told your GP / doctor practice that you are a carer?

91 responses



Information, guidance and support services

Do you feel your enquiry was dealt with promptly?

84 responses

As a result of either contacting or receiving support from Carers in Southampton, do you feel better able to continue providing care?

93 responses

Effect of Covid-19

- No Carers Lunches at present
- KIT calls
- Zoom wellbeing sessions delivered
- LAC - increased need
- Website stats show high searches for food, legal and hospital parking

Keeping in Touch during Covid-19

- Letter offering support at start of pandemic was sent to 3062 people to advise of services available including external vis ASC, So:Linked
- 2889 emails/KIT calls of which 1189 successful
- 28 carers opted for regular KIT support calls during pandemic peak and were contacted by phone weekly by the team at Southampton Mencap
- Calls indicated that many elderly single parent carers have recently been hospitalised from burnout

Effect of Covid-19

- Our website tracking stats between show an acute rise in searches for food support, for assisted shopping support (e.g. home delivery ordering by telephone), legal advice and hospital parking costs. See below:
  - Assisted shopping + 4,155%
  - Hospital ward nos. + 12,444%
  - UHS Parking charges + 474%
  - Contact us + 20%
  - Referral to CiS + 79%
  - Orgs w free legal advice + 124%
  - Food banks + 1,490%
  - Food services + 1,013%
  - Home Group + 25%
  - Emergency planning + 186%
  - Emergency tel. nos. + 121%
  - FAQ + 81%

My husband is now in full time care we used to go to the memory cafe as I visit him every day this is not possible at the moment. (Carers Survey 2019/20)

Sadly since 'joining' Carers we have been in lock down !! (Carers Survey 2019/20)

Life after caring

- Dealing with bereavement after being a carer can be an extremely difficult time, bringing a number of different losses:
  - The loss of the person
  - The loss of the caring role and the purpose and identity this gave you;
  - The loss of, or disconnection from, some of the things you may have given up or lost whilst you were a carer
- Particularly acute situation during Covid-19 with greater loss of life
- CiS supports carers in moving towards a life after caring with regular support sessions (currently online)

What works well overall

- Partnership and referral
  - Good collaboration with SCC and CCG
  - Referrals from ASC
  - Link worker with SCC
  - Cooperation from local hospitals/healthcare/clusters
    - Working with patient experience of care team at UHS
    - Banners, leaflets and newsletters at Western, RSH and UHS, Antelope House
  - Some star departments e.g. COPD and IDU engage and refer
  - Radio Solent (interviews and Christmas campaign)
  - Newsletter distribution partners (e.g. libraries/community centres)
- Self referrals (30% of total referrals)
- Website
  - 81% increase in visits - **11,173** in Q1 2018 vs **20,238** in Q1 2020
  - Referrals via website (accounts for 38% of self-referral)

What works well overall

- Carers Card very popular as method of self-identification
- Carers lunches currently suspended but previously well attended and good range of speakers
- Newsletter very well received with 816 downloads of last issue and much ad hoc positive feedback
- Life After Caring

The newsletter lists lots of helpful links for different situations which I can use for signposting in my churches. It must take a long time to put together but is really useful. (Carers Survey 2019/20)

What we want to achieve

- Inbound referrals from
    - Relevant medical departments
    - GPs (auto referral in prep)
    - Other support agencies
    - Self-referrers
- Outbound referral from our service to others
    - Automate referral within carers support plan process
    - Reduce burden on carers to repeat themselves constantly
- Wider provision of support for form filling
- Increase in emergency planning
    - 454 visits to EP page since Jan 2020, 348 since May 2020
    - 44 have accessed the EP form since May 2020, but only 4 have completed it online for SCC
- More TLC provision

Barriers

- Communication deficit
  - Local variation in carer services across UK blurs clinical understanding of Southampton offer
  - Generic misunderstanding of term 'carer' among entire population
  - Face time to explain our service offering as a simple proposition to
    - Medical departments
    - GPs
    - Other support agencies
- Referrals coming too late to be useful
- Outbound referral from our service to others
  - Automate referral within carers support plan process
  - Reduce burden on carers to repeat themselves constantly
- Delivering support to ageing carers who are digitally excluded and unable to access facilitation
- Wider provision of support for form filling
- Transport deficiency for carers to attend appointments and events within tight timeframes
- Meeting demand for Carers Assessment (10 week waiting list)
- Anticipated growth in demand – King's Fund project 61% increased demand by 2030 by the number of older people with care needs – such as help with washing and dressing
- Addressing wide range of carer support needs e.g. parent carers needing transport or educational access support; co-dependency of ageing LD community with ageing parents

I had my operation on February 11th this year and I have only just been contacted. My husband died on the 15t November 2019. (Carers Survey 2019/20)

Waiting for a carers assessment (Carers Survey 2019/20)

A glimpse of a better future

- Civil and military service employers identifying and referring employee carers
- Automated referrals
- Self-funders:
  - Soft support
  - Direction
  - Who does what mapping
  - Joined up services
- Formalised partnerships of 3rd sector agencies, perhaps facilitated by SCC
- Recognition of our Carers Card
  - At city leisure and cultural services (equivalent to MAX card)
  - Priority public transport and parking for carers at hospitals

Thank you from Carers in Southampton

CARERS IN SOUTHAMPTON
Helping unpaid carers

Phone: 023 8058 2387 Email: enquiries@carersinsouthampton.co.uk Website: www.carersinsouthampton.co.uk

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Agenda Item 8

Appendix 4

NO LIMITS

Helping Young People
Help Themselves

Young carers- definition

Children and Families Act 2014 Section 96

“…a person under 18 who provides or intends to provide care for another person (of any age, except where that care is provided for payment, pursuant to a contract or as voluntary work).”

NO LIMITS
Helping Young People
Help Themselves

Young carers in Southampton

Delivered by two 30-hour Young Carers workers

- No Limits received 126 referrals in 2019-2020
- Since April 2020 we have received 35 referrals
- We currently support 80 Young Carers across the city
- There are 466 young people under 15 in Southampton providing care, and a further 1,612 young people aged 16 - 25 (2011 Census).

NO LIMITS

Helping Young People
Help Themselves

Breakdown of who our young carers are caring for

Presenting Issue	Count of YP	%
cares for a sibling	28	35.00%
cares for an adult	37	46.25%
multiple care responsibilities	15	18.75%
Grand Total	80	

Care Needs of Person Cared For	Count of YP	%
Memory & cognition	1	1.25%
Mental health	37	46.25%
Physical: access & mobility only	6	7.50%
Physical: personal care	14	17.50%
Social: isolation/other	17	21.25%
Social: substance misuse	3	3.75%
(blank)	2	2.50%
Grand Total	80	

Young Carers postcodes

Post Code	**Count of YP**	**%**
SO14	4	5.00%
SO15	7	8.75%
SO16	31	38.75%
SO17	8	10.00%
SO18	11	13.75%
SO19	19	23.75%
Grand Total	80	

NO LIMITS
Helping Young People
Help Themselves

What we offer

No Limits supports Young Carers in Southampton both face to face and via Zoom:

- Family Assessment – looking at the needs of all family member which may result in sign posting/making referrals to other services across the City/Hampshire
- Young Carers Assessment - looking at the specific needs of the young person and what support is needed/wanted
- Delivering regular groups to provide the young people with knowledge, skills, respite, fun and soft outcomes sessions
- Delivering tailored workshops to the young people relating to their caring roles and their own needs (What is a Young Carer?, Looking After Myself)
- Providing 1:1 support for young carers with high levels of need in terms of their caring role
- Matching young carers with volunteer befrienders to provide positive relationships, build self-esteem, confidence and engage with new activities in their local community
- Providing fun activities and access to opportunities they might not otherwise be able to take part in
- Working with schools to develop Young Carers support in school

NO LIMITS
Helping Young People
Help Themselves

Views of our young carers -

WHAT BEING A YOUNG CARER MEANS TO ME?

Being a young carer means helping someone older than me because I help my parent

A young carer is someone who will always be there for their parent even if they've done it quite a lot and will always help

Caring for family

It's hard at times but its nice to know that I'm helping my sister

Views of our Young Carers -

THEIR EXPERIENCE OF OUR SERVICE:

Young carers in Southampton is very fun and social because we get to have fun and meet other young carers

We do a lot of activities, which is fun. Young carers in Southampton helps me clear my mind when I am really stressed

Having 'wacky' workers (in a good way)

Young carers in Southampton is a group that respects people

I feel free to talk about things

The Facts

- Young carers have significantly lower attainment at GCSE. The equivalent of nine grades lower overall than their peers.
- Young people from BAME communities are 1.5 times as likely as their peers to be young carers, and are twice as likely to not speak English as a first language
- Young carers are 1.5 times more likely than their peers to have a disability, long-term illness, or special educational need
- The average annual income for families with a young carer is £5000 less than families who do not have a young carer.
- Young carers are more likely than the national average to be NEET; more likely to be persistently NEET over 2 years; more likely to be in lower paid jobs than their peers in their early 20s

(The Children's Society: Hidden from View, 2013).

Impacts on our Young carers

- Physical injury/illness/developmental
- Emotional – anxiety/behaviour problems/mental ill health
- Worry and stress
- Educational – attendance and achievement
- Impacting on future life chances
- Social – Loneliness & Isolation and Hidden Harm
- Not sure how to relate to kids their own age
- No Concessions (recognised carers card)
- Lost transitions funding (18-25 year olds)

What our Young Carers are telling us

More Young Carers in the city than we can provide an ongoing service for

Days out, respite, fun activities and peer inclusion (what enables children to be children)

Transport- all other areas have transport support

Support for under 8s only support option is Honey Pots

Gap in provision 5-11years: lack of support services

A lot of Young Carers are being 'home schooled' and are not receiving and home schooling or education support.

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Carers Together

How we all fit into the jigsaw that is health and social care

Anne Meader
Carer Ambassador Carers UK
Carers Together, Hampshire Neurological Alliance,
Romsey and District Carers Forum, Hampshire Carers Partnership Board

Carers Together

- Carers Together is a Hampshire wide carer-led organisation established in 1993 to include Hampshire, Portsmouth and Southampton.
- It provides a voice for relatives, friends or neighbours who are caring for, or arranging care for, someone else.
- It represents carers views and needs locally and nationally.
- It is an independent organisation run by carers, with carers and for carers.

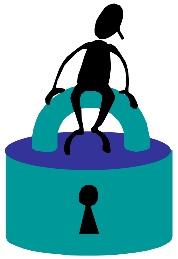
Some Historical facts

In 1998 Carers Together was invited to talk to the Hampshire wide Social Services Committee. We talked about Our Vision:

- Working in Partnership
- Meaningful Consultation
- Independence and Interdependence
- Joint Working
- Realistic financial support
- Real and Equal Representation
- Mutually agreed goal posts
- Recognition, Empowerment, Respect and Consideration
- Best Value and Real choice
- Accurate available and understandable information
- Informed, involved decision making
- Agreed Joint Strategy and Aims

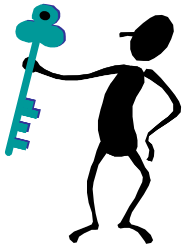
Some Key Words 1998

Carers (and service users) need and would like



- Accessibility
- Communication
- Community awareness
- Consideration
- Consultation
- Continuity
- Co-ordination
- Frankness
- Funding
- Independence
- Information
- Interdependence
- Openness
- Partnership
- Representation
- Resources
- Respite
- To be valued

- Choice
- Creative options
- Empowerment
- Equal status
- Equity
- Respect
- Recognition
- Responsive services
- Support
- Training
- Trust
- To be appreciated
- To be consulted
- To be enabled
- To be involved
- To be listened to
- To participate
- To represent themselves



2020 Plus Personalisation? Plus Coproduction?

Partnership from a carers perspective 1998

P	Partnership in planning
A	Ask us what we want
R	Respect our views
T	Two way dialogue
N	Negotiate with us
E	Equal partnership at all levels
R	Recognition
S	Sharing and caring
H	Hear what users and carers say
I	Information
P	Planning in partnership

Agreed joint strategy and aims 1998

At the end of the presentation we said:

- We know that Rome wasn’t built in a day, and we do not expect all our wishes, hopes or aspirations to be met at once.
- Remember we are very pragmatic and we are used to waiting for what we need and to managing on very small budgets.
- However we hope that some of the suggestions can be considered sooner rather than later and that we are soon all able to take small steps along the path to partnership in action.
- It does seem as though we have a long way to go.

Who is a carer?

A carer is

- someone who, without remuneration, has the main responsibility for providing or for arranging care for someone else who, because of long term illness, disability, or old age is not able to care for him/herself <u>or</u>
- anyone whose life is affected in any way by the illness, disability, age, frailness or health condition of someone else <u>or</u>
- someone who, without remuneration, has the main responsibility for providing or for arranging care for someone else <u>or</u>
- a person who gives support, help and assistance to a relative, friend or neighbour <u>or</u>
- anyone who provides or intends to provide a substantial amount of unpaid care on a regular basis <u>or</u>

BUT
There is no single, simple way of defining a carer because all carers are different individuals supporting different people with different needs

‘One challenge today is the ‘supposed definitions’ of a carer

- In fact they cannot be definitive because each description is different depending on who you are talking to.
- The label ‘carer’ is often made to suit the commissioners or providers of services so that the ‘carer’ fits the service they wish to provide. It is when organisations and commissioners start to look for someone who fits the label that the complications start.’
- Statutory organisations try to put people into identified boxes so they can clearly identify those they will or may help. However the boxes vary and are not the same across all statutory agencies or indeed within a statutory agency.
- If you talk to different people in different authorities, organisations or agencies you find a range of meanings depending on the service division, the funding available and the outlook of the individual professional.
- Many people do not recognise or accept that they are carers

The word ‘carer’

The word 'carer' refers to people who provide unpaid care to a relative, friend or neighbour who is in need of support because of mental or physical illness, old age or disability.

It does not include people who work as volunteers or paid carers; these people should be referred to as 'care workers'.

It is also important to remember that some people who use social services are also 'carers'. For example, many people with learning disabilities provide support to their ageing parents. **SCIE October 2005**

In reality

The term ‘carer’ has now been adopted by the public, care agencies, health and social care as referring to paid care workers

So it is very confusing now – ‘I cannot count the number of times someone has said what do you do, and when I say I am a carer – they reply who do you work for?’

Support for Carers

- ‘If you do not know the questions to ask, it is difficult to find the answers you need’
- ‘If you do not understand or accept the label - help and support may be delayed until you reach crisis’
- Giving people a label is the first step to dehumanising them’
- No single organisation or individual has all the answers for anyone – so commissioning needs to be innovative and flexible, creative and reliable, work in partnership and in coproduction
- Carers Support work should identify and look at carers holistically

‘Carers Support can be ‘Direct’ or ‘Indirect’ or ‘Community’

- **Direct Carers Support** - is provided by any organisation, service or group set up specifically to give support to carers. This can be in a range of different formats, methods and services but will have the primary aim of supporting carers.
- **Indirect Carers Support** - is provided by an organisation, service or group, statutory and/or voluntary, set up specifically to give support to people with a specific disability, medical condition or illness but which gives considerable support to carers, deliberately or by default, because of the support they give to the person being cared-for and the networks and information they establish.
- **Community Carers Support** - is provided by a wide range of organisations, services and groups, statutory and/or voluntary, that provide a range of community facilities that carers can tap into as and when needed. These will not be specifically for people with disabilities or carers but will be available to any citizen on a basis of need e.g. Voluntary Services, CAB, Red Cross, waste management, public transport etc.

Some points to consider

Some points to consider:

- Carers are people first!
- People are individuals with individual needs.
- Carers have a range of needs as people <u>and</u> as carers!
- Some of their caring needs can be met as people, some need specific expertise and caring support.
- How people care is as different as the number of different people in the world.
- Carers can be any age and ability.
- Approximately 1 in 8 people is a carer (that could include an eighth of any workforce), 74% are older people, 75% of older people do not actively receive health and social care support. **It is estimated that the number has increased during the pandemic**

Suggestions

- We should find out what carers say is most important to them and what would make a difference. (The carers group of the Hampshire Carers Partnership Board has a list of their priorities)
- We should continue to encourage GPs to develop their register of carers – and signposting carers to services that can support them (possibly either through Care Navigators or Social Prescribers)
- Organisations and businesses should be encouraged to identify the carers in their work force and wherever possible offer flexibility and support to help carers remain in work
- Having a Carers Champion in each organisation would help
- Look at the services currently provided and compare them with the list developed by carers over 20 years – what has changed and what impact has the Pandemic had so far?
- Look at other ways communities can support carers – some identified through the Pandemic

Coproduction

- Coproduction is a reciprocal coproduction of activities by professionals and citizens.
- It shares the planning, design and delivery of services, recognising that both need to contribute equally in order to improve quality of life for people and communities.
- Coproduction helps to ensure that resources are used wisely to develop the services that people really want and need.
- It produces better outcomes for carers and people with lived experience and can help build stronger communities and develop citizenship – working together to make things better

Coproduction

- Include the people most affected by what you do or are planning to do at the heart of the work – from design to implementation and monitoring
- A culture change for most professionals and people who use services
- Plan for the future – together – use the coproduction checklist
- Services users and carers are everywhere – staff, volunteers often need simple solutions – to achieve major improvements
- Coproduction saves time and money in the long term

Then what next? Service users and carers as leaders?

Partnership

- Real partnership – not just a tick box
- Best way – not necessarily the old way
- Thinking how to achieve it - equal opportunities, agreeing goalposts, communication
- Using the carer experience and expertise already there
- Things to think about - people/organisations to involve, work together, lots of answers
- Compassionate Communities
- Safeguarding and taking risks – be positive
- What can good housing do? Sheltered, extra care, appropriate to the needs of carers and individuals ………….
- Support Planning Partnership
- Carers Partnership – led by carers

No single organisation or individual has all the answers for everyone

- ‘Carers are all service users’
- Not just health and social care services but a range of services in the community including police, ambulance, fire service, transport, housing, waste disposal, libraries, shops, leisure services, village/community halls services etc.’
- Some organisations e.g. Southern Health, are developing an Active Carers Strategy. They are listening to carers, gathering Carers Stories, making a commitment to improve the experience of carers, have joined the Hampshire Carers Partnership, identified what they need to improve, and are also developing a coproduction strategy.
- Others such as UHS have appointed a Carers Support Worker and are also developing their carers strategy.

Suggestions

- Surely a good move would be to coordinate all the Strategies so carers are at the centre and ideas and actions can be coordinated?
- Work with HYCA to help find solutions for Young Carers
- Ensure that a Carers Strategy meets the wishes, ideas and suggestions of carers and is a Joint Strategy with other organisations that support carers – so carers are at the heart and their needs are met in a coordinated way
- Ensure there is an Action Plan to help the continuation of positive solutions and the implementation of new services, new and innovative ideas in partnership, personalised and coproductive way

Suggestion

- ‘Statutory organisations need to change their culture and work in coproduction with carers and people with lived experience, as well as other stakeholders, to ensure they are involved in the development, design and provision of services to meet their real needs.’
- Gather the views from carers and listen to the voices of those with lived experience
- Think about how to harness what is already there, but not yet being maximised for optimum outcomes
- Communicate and work with all the organisations around that support carers e.g. Southern Health, Solent, UHS
- Think about developing a Carers Charter that all organisations can be asked to sign up to

The Health and Care Jigsaw

- It is held together by carers, and the people they care for - without them, health and community care services would collapse
- Everyone is different - make sure you ask carers the right questions and find person centred answers
- Find out what the carer can do, what are their needs, how they receive help, how they can be supported, how they are treated and respected.
- Don’t assume you know what to do - or have all the answers
- Use the carers knowledge and acknowledge they a have a role to play
- Reach out to people in a caring role who do not identify themselves as carers – learn from other initiatives that are happening outside the City
- Do not assume that it is OK just to put information on the Web. It is important to also develop other ways of reaching out

The effect of the Pandemic

- What has changed due to the Pandemic – for the worse, for the better? Work out how to use the experiences to bring about positive change
- Not being able to visit the person you care for if they are living elsewhere. Why can't a carer be designated a key worker?
- Having a break from caring is essential to enable a carer to carry on caring. It is not a new problem, it has been a priority for carers for many years. It is not the same for each carer as they are all different with different caring responsibilities.
  - Some need regular daily or weekly time off, some manage with 2 hours a week.
  - Some need a period of time away from home to enjoy a relaxing break in a centre that understand their needs.
  - Some want a break from the person they care for others want a break with them
- During the Pandemic, breaks have disappeared or been greatly reduced. How can this be relieved, reinstated or improved in future?
- A number of surveys with useful ideas/suggestions have been published during the pandemic and a survey of carers is currently being undertaken by Healthwatch Hampshire

Interesting and useful information, documents, resources and books

Keeping in touch with change - use all resources including:

- www.gov.uk
- www.parliament.uk
- www.nhs.gov.uk and CCG Websites
- www.kingsfund.org.uk
- www.carerstogether.org.uk
- www.thinklocalactpersonal.org.uk
- www.scie.org.uk
- www.nationalvoices.org.uk
- CQC www.cqc.org.uk/
- NICE www.nice.org.uk/
- DWP www.dwp.gov.uk/
- Carers UK www.carersuk.org

Interesting and useful documents and books

Books, articles, electronic sources e.g.

- **Carers and their Rights - the law relating to carers**

  This guide (7th edition) describes the legal rights of carers as they apply in England and Wales. It was written by Luke Clements, Luke Clements is the Cerebra Professor of Law and Social Justice at the School of Law, Leeds University

  http://www.lukeclements.co.uk/wp-content/uploads/ 2018/05/7th-ed-draft-Carers-Guide-11.pdf

- Care and Support Guidance - https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#using-the-care-act-guidance
- **Selfish Pigs Guide to Caring – Hugh Marriot**
- **Extreme Caring – you have to go on - Stuart Donnan**
- Carers Together – Key Statements (email admin@carerstogether.org.uk – for a copy)
- Caring Behind closed doors - forgotten families in the coronavirus pandemic - Carers UK
- Information, Services and Support – in Hampshire and the Isle of Wight during the coronavirus pandemic - Healthwatch Hampshire 25 06 20

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Carers Together

How we all fit into the jigsaw that is health and social care

Anne Meader
Carer Ambassador Carers UK
Carers Together, Hampshire Neurological Alliance,
Romsey and District Carers Forum, Hampshire Carers Partnership Board

Why Carers Together was set up

It was set up to:

- Listen to carers and identify their needs and priorities
- Develop the profile of carers and form a larger and stronger voice for carers
- Try to ensure carers are offered informed choices
- Promote local carers services and groups
- Support and link local networks
- Encourage partnerships and working together
- Provide information resources
- Signpost carers to services to help them
- Start to promote the Ladder of Participation (Sherry Arnstein 1969)

What CT Does

It responds to the needs identified by carers – either providing or promoting services that will help them

- Advice
- Advocacy – independent, peer, individual
- Awareness,
- Benefits Advice & Support as an alternative office for DWP
- Carers Drop-ins at different sites & centres
- Carers Information Packs
- Carers Support Groups
- Carers Network Events.
- CALL - Free telephone emotional support - 365 days a year – CALL 08000 3 23456
- Information and Signposting

What CT does

- Mobile Information Trolley – at Southampton Hospital
- Mobile Information Vehicle – in the community
- Newsletters (usually email or facebook now)
- Payroll and Employment Service for people employing their own staff
- Personal planning – Say it Once - LPAs, Advance Care Plans, Personal Profiles, Care Preferences, Wills, Funeral Planning
- Support Planning
- Support with Direct Payments/Personal Budgets
- Support with self-directed support and personalisation
- Training and Awareness courses for carers
- Training and Awareness courses for professionals
- Your Choice Your Support - Respite/take-a-break service,

Current CT Projects

- Carers Training and Awareness – including how to self advocate and how to take an active part in meetings, events, activities.
- Training for professionals in carers issues
- End of caring project – how to see it from the carers perspective
- Your Choice Your Support
- Romsey Rendezvous – community drop-in – no labels here
- Carers Drop-ins at different community sites – and follow up support
- Hospital Information Trolley – and other developments
- Support for families of people with long term health conditions – joint work with Hampshire Neurological Alliance – Information about long term neurological conditions and Knowledge Network
- Hampshire Carers Partnership Board

Interesting and useful information, documents, resources and books

Keeping in touch with change - use all resources including:

- CQC www.cqc.org.uk/
- NICE www.nice.org.uk/
- DWP www.dwp.gov.uk/
- Carers UK www.carersuk.org
- www.gov.uk
- www.parliament.uk
- www.nhs.gov.uk and CCG Websites
- www.kingsfund.org.uk
- www.carerstogether.org.uk
- www.thinklocalactpersonal.org.uk
- www.scie.org.uk
- www.nationalvoices.org.uk

Interesting and useful documents and books

Books, articles, electronic sources e.g.

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- Care and Support Guidance - https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#using-the-care-act-guidance
- **Selfish Pigs Guide to Caring – Hugh Marriot**
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Caring in Partnership
Partnership in Caring

Agenda Item 8

Appendix 7

Annual Statement

by

Carers Together

August 2020

Coproduction is a reciprocal coproduction of activities by professionals and citizens. It shares the planning and delivery of services, recognising that both need to contribute equally in order to improve quality of life for people and communities and achieve better outcomes.

Coproduction helps to ensure that resources are used wisely to develop the services that people really want and need. It produces better outcomes for carers and people with lived experience and can help build stronger communities and develop citizenship

In this document the word 'carer' means an unpaid, informal relative, friend or neighbour who supports or helps someone who is disabled, has a long or short term medical condition or illness or is an older person

© Carers Together 2002; Revised August 2004; November 2005; July 2006; November 2007; October 2008; October 2009; October 2011; October 2012; October 2013; October 2014; October 2015; August 2016; August 2018, August 2019, August 2020

Carers Together in Hampshire first produced this report in 2002.
It is updated annually (more often if necessary) to respond to the changing situation for carers.

CARERS KEY STATEMENTS

'Coproduction is a reciprocal partnership of professionals and citizens. It shares the planning and delivery of services, recognising that both need to contribute in order to improve quality of life for people and communities.'

Coproduction helps to ensure that resources are used to develop the services that people really want and need. It produces better outcomes for people who use services and carers and can help build stronger communities and develops citizenship

‘Self-directed support, personalisation, prevention and early intervention need to become a reality if carers are to receive the right support at the right time. This includes encouraging and supporting people to prepare and plan for the future themselves not waiting until people reach crisis.

This also needs a culture change in both health and social care to enable individuals with lived experience to be involved and if possible lead the direction of services at every level and in every project that affects them’

‘There is no single answer to the problem of how to reach anyone (including carers and people with lived experience) with information, advice and support when they do not know or understand that they are carers or that they have needs that could be met.’

‘If you do not know the questions to ask, it is difficult to find the answers you need’

‘If you do not understand or accept the label - help and support may be delayed until you reach crisis’

‘Often, there is a big gap between the point of diagnosis and the point when someone needs active or intense health or social support.’

‘Part of the problem is the ‘supposed definitions’ of a carer. In fact they cannot be definitive because each description is different depending on who you are talking to.

The label ‘carer’ is often made to suit the commissioners/providers of services so that the ‘carer’ fits the service they wish to provide. It is when organisations and commissioners start to look for someone who fits a label that the complications start.’

‘Another problem is the artificial labels created by health and social care to describe people.

Basically the barrier to receiving support is the perceived need for people to be labelled in order to access any support available.

The labels can themselves be confusing and divisive not least because health and social care use different labels’

Giving people a label is the first step to dehumanising them’

‘Coproduction is a way of working that ensures statutory organisations give a total commitment to co-design and joint implementation with the people who use services.
It cannot be used selectively or withdrawn when organisations chose to work differently’

‘Statutory organisations need to change their culture and work in coproduction with carers and people with lived experience to ensure they are involved in the development and provision of services to meet their real needs.’

Say it Once and the Personal Profile will encourage individuals to take control of their own information needs and reduce the number of times carers have to repeat their information and the information of the person they care for.
‘Carers are all service users. Not just health and social care services - but a range of services in the community including police, ambulance, fire service, transport, housing, waste disposal, libraries, shops, village/community halls, leisure services etc.’
‘A carer is a person first, therefore planning and support for any carer should be holistic and person-centred and mean a carer’s needs are met as an individual and as a carer’
‘Independent individual single issue advocacy for carers is a key to good carers support. It ensures that carers have access to good information about their rights and appropriate support as and when they need it’
‘Carers Support should be a carer-led, independent, flexible and responsive service to meet the changing and developing needs of a wide range of individual carers’
‘An effective Carers Strategy will reflect the views of carers, be flexible and acknowledge that it cannot be definitive, but will point to a desirable focus for carers and their support’. There must be an Action Plan with every Strategy so it does not sit on the shelf until the new review date.
‘Caring is not a paid occupation. It involves emotional and practical support between individuals who are all different’
‘Caring is not an exact science because no carer is the same as another’
‘There are several statements that can describe a carer because it is impossible to give a single overarching description that has real meaning for all the people in a caring role’
‘Simply – all carers are different, caring for and about different people, who themselves are all individual’
‘Carers support is not the prerogative of any one organisation’
‘Carers Support can be ‘Direct’ or ‘Indirect’ or ‘Community’
‘The situation is no different from 1993, when carers were struggling for recognition, respect, support, respite and information’
‘Services that give best value are constantly monitoring themselves and the situation around them’
‘Carers need a range of solutions that fit key words such as choice, information, best value, added value, partnership, cooperation, coordination, flexibility, responsiveness’
‘There is no simple solution, but there are some very clear pointers, that could lead to better carer satisfaction’
‘The Government has issued a number of guidelines stating that support services for carers must be seen to be independent and carer led’
‘Services are only valued if they meet the individual needs of the carer’
‘Some services are probably better supplied in-house by statutory organisations’
‘Some services are better supplied outside statutory authorities’

'Carers Together provides flexible, person-centred, responsive carers support'
'People live their lives as individuals and need to be able to make real choices, take their own risks and have control of their own lives – but they need to be connected to the community in which they live in whichever way suits them'
'All people live in localities and communities of different sizes and constitutions. Helping people to work together in their local community is the best way to provide support and identify people's strengths so they able to make real choice to meet their actual needs.'

Further Information on many of the statements is available below

'A carer is a person first, therefore planning and support for any carer should be holistic and person-centred so their needs are met as an individual and as a carer'

All people should be treated as individuals with individual needs, goals and rights. Carers give their time and commitment to supporting others but this should not mean their own needs should be ignored.

All assessments and service provision should look at the needs of the individual and if they happen to be a carer, it may mean they need additional support so they can meet their own needs, as well as the needs of the person they care for.

They should not be 'lumped in' with any assessment of the needs of the person they care for as though their needs are secondary

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'Carers Support should be a carer and needs led, independent, flexible and responsive service to meet the changing and developing needs of a wide range of individuals'

Carers support means something different to each individual carer. There is no simple way to give or offer carers support because the needs of individual carers vary according to each carer and their cared-for person. However, many carers find that the similarities between their circumstances and needs mean they can empathise with each other and help to develop mutual support mechanisms.

These mutual support mechanisms (peer support) have developed because most carers recognise the needs of other carers even though their circumstances may be different. They want to decide for themselves what they need (sometimes with support), receive information so they can make informed choices not be told what to do or have other telling them what is best.

This mean the direct input of carers at all levels of all statutory and voluntary organisations that purport to 'give' carers support and regular review of what is provided to meet the changing needs of different carers.

'An effective Carers Strategy will reflect the views of carers, be flexible and acknowledge that it cannot be definitive but will point to a desirable focus for carers services and support'

A strategy is a systematic plan, produced as result of a comprehensive consultation process, to identify the proposed future action and overall direction of an organisation, network or partnership. It should include a vision of excellence.

It is a written statement of what an organisation should be doing to achieve the objectives identified during the strategy consultation.

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It should have no finite start or end dates, but should be constantly evolving in the light of ongoing experience, dialogue, feedback, consultation and change in government directives/legislation.
There must be an Action Plan with every Strategy so it does not sit on the shelf until the new review date.

‘Independent individual single issue peer advocacy for carers is key to good carers support’

Independent individual single-issue advocacy ensures that carers have access to effective independent support and information about their rights and responsibilities when they need it. It means they will be supported each time to achieve the best outcome for them. Individual carers champions should be trained and experienced in ensuring that the carer’s views and wishes are understood and paramount

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‘Caring is not a paid occupation’

It involves emotional and practical support between individuals who are all different

Caring is part of a personal relationship between two or more people who are emotionally bound by a mutual need or concern.

Our English word 'care' comes from an old English word. The verb means 'to feel concern or interest for', 'to provide food or attention for'. The noun is defined by the dictionary as 'solicitude, anxiety, heed, caution, pains, serious attention, charge, protection.'

Paid workers, who work with carers and the people they care for, are not carers. They are care workers who support and work with carers and the people they care for.

‘Caring is not an exact science because no carer is the same as another’

The way someone cares depends on a range of factors including: the person, their personality, the support they receive, the family they have, the friends who understand, the professionals linked to them, their GP network, the hospital nearest to them, the person they care for and their disability.

Any individual can be both carers and dependent at the same time or can move backward and forward between the roles.

In his/her lifetime a carer can readily interchange between dependency and caring. Everyone at some time becomes a dependent and everyone at some time becomes a carer, although many do not recognise the roles.

A parent may be caring for a child with a recognised disability. Although there may be other children with the same identified disability, every disabled person is an individual with some of the inherited genes of their parents and some of the inherited genes of the disability. They are all different individuals, even when in the same family, and their specific care needs are also different.

A parent may also be caring for his/her parent and have torn loyalties. One parent of a child with disabilities may develop a disability and become a parent carer who is also dependent on the other parent, a relative or friend. Computations and variations in caring are ever changing and endless.

‘All carers are different, caring for and about different people, who themselves are all individual and different’

There are as many different carers in the world as there are different people.

© Carers Together 2020

Each person is an individual with their own needs, rights and responsibilities that belong to them.

This does not change because they are a carer.

Although they may have some common wishes, needs, or responsibilities each carer will approach them differently, so support will need to be appropriate for each individual.

‘There are several statements that can describe a carer’

- A carer is someone who, without remuneration, has the main responsibility for providing or for arranging care for someone else who, because of long-term illness, disability, or old age is not able to care for him or herself
- A carer is a person who gives support and assistance to a relative, friend or neighbour who has an illness or chronic condition
- A carer is anyone who provides or intends to provide a substantial amount of care on a regular basis.
- The word 'carer' refers to people who provide unpaid care to a relative, friend or neighbour who is in need of support because of mental or physical illness, old age or disability.

  It does not include people who work as volunteers or paid carers; these people should be referred to as 'care workers'.

  It is also important to remember that some people who use social services are also 'carers'. For example, many people with learning disabilities provide support to their ageing parents. (Social Care Institute for Excellence SCIE October 2005)
- The term carer refers to anyone who cares for another person and is not paid for it. Caring duties can range from helping someone with the shopping to giving 24-hour care. (CSCI 2006)

It is impossible to create a single simple description of a typical carer because there is no average carer who could fit the mould. This dichotomy makes it difficult to create a carers support service, as a single separate individual service that meets carers needs.

In no case is there a simple, single example of caring that can be called typical, but there is always a need for help, support, advocacy, counselling, friendship and understanding.

Carers come from every walk of life, from any career, and bring with them a wide range of skills and experience. Because they are all different, carers need a wide range of flexible support to help them to manage their own time effectively, and have a break from caring when, how/where needed.

‘Carers Support can be ‘Direct’ or ‘Indirect’ or ‘Community’

Direct Carers Support - is provided by an organisation, service or group set up specifically to give support to carers. This can be in a range of different formats, methods and services but will have the primary aim of supporting carers.

Indirect Carers Support - is provided by an organisation, service or group, statutory and/or voluntary, set up specifically to give support to people with a specific disability, medical condition or illness but which give considerable support to carers, deliberately or by default, because of the support they give to the person being cared-for and the networks and information they establish.

Community Carers Support - is provided by a wide range of organisations, services and groups, statutory and/or voluntary, that provide a range of community facilities that carers

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can tap into as and when needed. These will not be specifically for people with disabilities or carers but will be available to any citizen on a basis of need e.g. Voluntary Services, CAB, Red Cross, waste management, roads etc.

'Carers Support is not the prerogative of any one organisation'

Carers support is not the prerogative of any one organisation and it does not need to have 'carer' or 'support' in its title to provide excellent support services for carers.
Carers Support is often piecemeal, with different organisations/groups competing for limited funds to provide formal, recognised, carers support to meet different aspects of perceived carers needs.

No single authority or voluntary organisation can provide all services to meet all needs.

Until it is accepted that there is no typical carer with average needs and wishes, support for carers will continue to be less than satisfactory and authorities continue to fail to meet their duty to give appropriate individual Carers Support based on an assessment of individual need.

'The situation is no different from 18 years ago, when carers were struggling for recognition, respect, support and information'

The response by different authorities was piecemeal and, until the Government Carers Strategy in 1995, there was no identified acceptance of 'Carer' as a recognised role.

Some statutory authorities have a very good awareness of carers; most recognise the value of having a 'carer' for the person with an illness or disability; many provide a range of carers support based on historical demands and reports over the years. None of this is bad, and credit should not be taken from those authorities, which have moved forward on the lines of previous recommendations and reports.

However, it is now a time of reducing financial stability for authorities and voluntary organisations involved with carers. It is therefore a good time to re-examine the current levels and type of support and investigate if they are all giving best value.

'Services that give best value constantly monitor themselves and the situation around them'

They need to be honest about what they provide and consult regularly on what is needed. They need to respond positively to changing needs and be open about what they can do and what others may better achieve.

It is important for organisations to look at their service provision and seek best value responses i.e. essential (challenge), needed or wanted (consult), desirable (compare), cost effective (compete).

One of the main problems for carers, and those that support them, is that very often the carer does not know what he/she really wants until they have been caring for while, and it is therefore with gratitude that they accept whatever is offered initially. In many cases, they are then so afraid that the service will be removed and they will be left with nothing, that they are frightened to complain, or say what they really want.

There are many examples of this and much is related to subjective factors e.g.

- carers may like or dislike the social worker,
- fear or love the home carer,
- hate or like the day centre, would prefer different times and days,

- need a break but feel they must accept the local residential home on offer when they would prefer to go away with the person they care for or have care in their own home.

Another problem is that local authorities have traditionally based their services around buildings and existing group services such as day centres, residential homes, carers centres etc. Having invested their money in these services, they feel that they have either met their obligations to carers, or must use the services to warrant the level of financial support needed to maintain the high cost, highly resourced buildings and centres.

Over many years the overhead costs of statutory and voluntary organisations have grown out of all proportion to services. Although these are often essential to enable them to meet their legal obligations, it is very difficult for an authority to separate the commissioning, monitoring role from the role of providing services and support. This also has an effect on their perceived failure in meeting the real and multi-varied needs of carers.

Change in service provision should reflect the majority needs and wishes of carers as well as the changing situation around them – they should be seen to be responding to the wishes of carers and not just to the current financial situation or statutory policy

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‘Carers need a range of solutions that fit key words such as choice, information, best value, added value, partnership, cooperation, coordination, flexibility, responsiveness’

In order to achieve flexible and responsive solutions, it is essential to consult carers at every level and offer an individual, purpose built package of care on every occasion (Service Brokerage). The only way for this to be possible is for health, social services and the voluntary sector to give a real commitment to consultation with carers and to respond to the changing and evolving individual needs being identified.

In other words **challenge, compare, consult and compete** in an open forum.
Token consultation with one or two carers outnumbered by the people and groups that have a vested interest (whether in the status quo, or in increasing their own input), does not seem to meet the best value principle, or identify/meet the needs of individual carers.

‘There is no single simple solution, but there are some very clear pointers, that could lead to better carer satisfaction’

Carers need to work with Social Services as well as a wide range of other statutory agencies such as Social Prescribers, Primary Care Trusts (PCTs), Hospital Trusts, Strategic Health Authorities, Patient Advice and Liaison Services (PALS), Patient and Public Involvement Forums, Patient Forums, Local Strategic Partnerships, District Councils and Education.

Statutory organisations and agencies are required to consult with people who use their services and this can put a tremendous consultation and/or representative burden on carers unless the different agencies work together with them to achieve cohesive, cost efficient and effective results. Sometimes the consultation is perceived by carers as ‘tokenistic’.

Joint working and pooled spending would achieve more than piecemeal action and would be less time consuming and achieve added value, especially if added to and coordinated with resources gained by local and countywide carers organisations from other sources.

There are many groups, organisations, public and private agencies already providing a wide range of ‘general’ services and support that carers are able to tap into. Authorities could enhance these by enabling the carers to access the particular service, support or activity that is wanted, needed or required by each individual carer.

Most carers want to live ‘as normally as possible’ within the caring role and may need

- support to manage their time
- a friend (or friends) in need to give the individual support required
- time out to do the things they enjoy, or try new things with other people who are not necessarily carers.

‘The Government has issued a number of recent guidelines stating that carers support services must be seen to be independent and carer led’

Instead of statutory/voluntary agencies trying to push through changes, or bringing in new organisations, is it better to work together to look at and help enhance what is already there? This is better use of funding and does not create operational competition, which can happen if there are two or more services providing direct carers support services in an area. Carers do not understand or want that and feel they are torn between them.

Why re-invent the wheel? What is the advantage of using public funds to set up two or more services in opposition? How can public authorities and departments warrant funding a carers’ service, which will then be in competition with a registered charity or constituted body already operating in an area, and which has accessed funds from other sources to enhance the service provision for carers? This includes national charities (e.g. MIND, SCOPE, MENCAP, RETHINK) as well as local charities (e.g. Wessex Cancer Care, Alzheimer’s, Carers Together, Carers Forums, local independent user-led organisations

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‘Services are only valued if they meet the individual needs of the carer’

- **Support groups**
  Support groups may be one answer. Some carers want a support group, and need to know that there are other people with similar problems, that they are not alone and that it is ‘OK’ to be sad, angry, frustrated etc, but many express a preference for contact with other carers in different ways e.g. telephone, personal visits, email, internet. It is often impossible because of their caring role to meet on fixed days and at fixed times.

  Carers Support Groups are often underused. Several carers have said ‘I go to the carers support group once month because I feel sorry for the person running it – she puts such a lot into it and very few people turn up so I feel I must’. Some find a carers support group invaluable, some prefer to go to specialist groups run by a range of organisations, some prefer general support. The variety of needs make it difficult to provide a standard carers support group and one that flexibly meets local carers needs is probably most beneficial.
- **Assessment of individual needs is essential**
  This includes assessing needs and helping carers to find the right package of care for them, helping with finance issues for the carer and the person they care for, giving them the opportunity to take advice from independent Direct Payments workers and monitoring the ongoing needs and service provision. Single Assessment Process (SAP) should provide a better, more coordinated service for carers and the people for whom they care.
- **Information**
  Information is necessary for carers and people who are disabled. The information they need is wide-ranging and provided by lots of different people and organisations. Many carers have expressed the need to have accurate information, up to date and available when they need it and where they need it. They want a comprehensive information service that they can access where they happen to be, not have to go from place to

place to access it. This needs cooperation from all groups in each locality, to work together and provide accurate comprehensive information about the range of services in the local area for all the citizens e.g. Romsey Area Information Network (RAIN). It is a task being looked at by some District Councils as part of their Local Strategic Partnership.

- **Carers need an independent, non-judgemental, confidential listening ear.** They need to know they can offload all their frustrations or just ring for a chat when things are getting them down. They need to know that the person on the telephone is independent and not from Health or Social Services, as otherwise they cannot express some of the frustrations they have with those services.

  A ‘Listening Ear’ for carers is best provided outside the management of statutory bodies who need to run their own out of hours and emergency services as part of their own service provision. The carers support element should be seen to be separate at all times so the people staffing the service can advocate for them with the authorities if necessary. This service could also be provided more cost effectively by an independent organisation.

- **Carers Networks**
  Carers Networks are growing as carers realise that they can become part of a changing network of support, information, listening, advocacy and mutual interests. Networks can link carers through different channels of communication, training, signposting and information. They can include Carers Awareness Courses, activity ideas, first aid, advocacy, financial awareness, email, telephone, Internet, relaxation and personal contact. Carers Networks need to be flexible, developing and changing to meet the needs of individuals and should go out to where carers are rather than expect carers always to come in to a centre. Carers Networks can only be achieved outside the management of public authorities and are better based in an umbrella carers organisation, which is continually responsive to the changing needs of carers.

- **Take a Break Services**
  Sitting services are a recognised support that is personal, and as far as possible, meets the times and days of the carers choice. However, many carers say they want to use this limited time to do shopping, or visit friends or do a leisure activity rather than meet with other carers or have their time arranged for them. Most sitting services offer fixed times and days which is helpful in planning time off but does not meet the need for emergency or surprise activity. This needs a more flexible approach to choice and respite care.

- **Respite care**
  Respite care in the form of day care, sitting, cleaning, personal care and residential care can be made available as an in-house service or through effective commissioning, but respite care should not only consist of this small number of identified services.

  Each individual will have a different idea of what respite means to them and service commissioners should be flexible to match the service provision to the carer’s needs not expect the carer to fit into the parameters of services they have established.

  This will mean putting financial and other resources into an ever-changing supply of flexible and different community and respite services e.g. befriending. It may be difficult if not impossible for Social Services to maintain all their in-house respite and care services, which need high funding commitments. It is possible there will be a need to rationalise the level and supply of building based respite and to offer flexible and more effective services as a result.

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‘Some services are probably better supplied in-house by statutory organisations’

These include commissioning in a wider sense; independent and unbiased information about residential, domiciliary and day service provision (already provided and available annually in Hampshire and much valued) and an input into assessment of individual need.

However, assessment of needs (carers or dependents) should not be undertaken by any organisation in isolation. It should be the result of multi-agency, multi-disciplinary input with major input from the person themselves and their carer. Possible solutions need to be responsive to individual need and include a range of services that may have an input.

Commissioning, information and assessment form part of the duty of care of statutory organisations and should be undertaken in partnership with others. Partnerships could be led by carers – it does not always have to be led by statutory organisations e.g. RAIN, RADISH.

Provision of services needs to be looked at individually and separately – however all services need to work together to provide a coordinated service that make best use of limited resources and gives a comprehensive, efficient, effective and professional service.

‘Some services are better supplied outside statutory authorities’

Carers should be supported appropriately to the locality where people live, making use of the range of carers support already available, direct, indirect and community.

Duplicating services or creating complicated systems where more than one service is operating in an area cannot be seen to be cost or personnel effective. Nor does it provide a clear line of support for carers who are already struggling with the complicated procedures they have to go through in order to get any support at all.

Where there are gaps in provision, the development of services should be promoted to fill the gaps. This should not just be ‘named’ carers services, but a range and variety of services to meet individual needs whatever they are.

What do carers really want? Is it really being supplied or is it time to grasp the nettle and propose something different? Why change or continue with the status quo if rationalising or working together can achieve added value?

Some services are better led by carers. These include:
- Carers Support e.g. Peer Support
- Carers Information
- A Carers Listening Service e.g. Carers Active Listening Line
- Clear Action Planning – SIO Programme
- Carers Awareness
- Carers Training
- Carers Activities

These should all be led by ‘carers voice’ organisations in each natural locality but linked and supported by a wider ‘partnership’ network to help share good practice, give administrative support and encourage equity.

To be really effective they need consistent funding and resources. Funding agreements are temporary or short term. Some service level agreements provide advice and support across the whole of Hampshire (excluding Southampton and Portsmouth). Others provide carers support in specific social services areas of the county. Some provide carers support in Southampton. There is no single organisation that can supply all the answers. Carers Together is one organisation that provides direct support to carers.

‘One problem is the ‘supposed definitions’ of a carer.

In fact they cannot be definitive because each description is different depending on who you are talking to.

The label ‘carer’ is often made to suit the commissioners or providers of services so that the ‘carer’ fits the service they wish to provide. It is when organisations and commissioners start to look for someone who fits the label that the complications start.’

Statutory organisations try to put people into identified boxes so they can clearly identify those they will or may help. However the boxes vary and are not the same across all statutory agencies or indeed within a statutory agency.

If you talk to different people in different authorities, organisations or agencies you find a range of meanings depending on the service division, the funding available and the outlook of the individual professional.

‘Another is the artificial labels created by health and social care to describe people.’

Basically the barrier to receiving support is the perceived need for people to be labelled in order to access any support available. The labels can themselves be confusing and divisive not least because health and social care use different labels’

Social Care is provided under the broad headings of:

  - Physical Impairment
  - Learning Disability
  - Autism
  - Sensory Loss
  - Mental Health
  - Older People (when did older people become a health or social care condition?)
- Health Care is provided under the broad headings of:
  - Illness
  - frailty (often related to old age)
  - health condition - short term condition
  - health condition - long term condition
  - health condition - terminal

This mixture of conditions, needs and age does not lend itself to efficient or effective ways of working, nor does it help people to work through their own real and personal issues and the potential solutions.

People are labelled and cared-for rather than supported to develop and grow as individuals who can also utilise their own assets, and this takes away opportunities to find potential innovative support they need and/or want.

None of the health and social care services deal with the holistic person - who may have more than one condition, or may be dealing with other issues including family, work, housing, education, transport, community etc.

As a result people often do not know about the range of activities and services available to them in the local community and it may mean that people’s own skills and talents are not recognised or used. This is a constant concern.

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‘Carers Together provides flexible and responsive carers support’

The boundaries of Social Service and Health areas have changed at least three times in the last 15 years and Carers Together made the decision some time ago to undertake its work within its area of benefit and in natural localities.

As part of its aims and objectives Carers Together produces a countywide newsletter and welcome articles and input from other groups and organisations.

It regularly invites carers from across the whole county to be involved with consultations to ensure they have a voice in local, county and national issues.

Funding is received from a range of sources, health, social services, education and voluntary to provide particular, specific and general carers services in different areas and for different purposes.

Carers Together has always provided carers support to any carer in historic Hampshire and works with the wide range of services, groups and organisations that give support to carers both directly and indirectly in every area.

For many years it has had regular contact with every GP surgery in Hampshire and has recently, in consultation with several GP surgeries, developed a Carers Registration form and system, which has had a substantial and positive response.

Carers can access services already available in the community such as advocacy (very limited at present), counselling, sitting, cleaning, befriending, financial advice, leisure. Arranging for the carer (and funding it when necessary) to access existing services, helps prevent the need to set up specialist services for carers that are often underused.

There is considerable value in having an independent umbrella organisation to support and maintain some equity across the wider county area, working side by side with local Carers Forums based on

local natural localities rather than artificial areas created (by health, social services, education and other statutory bodies) solely for dividing population numbers.

Independent Carers Forums have the added benefit whereby they can apply to others sources for funding and work together with other groups in the locality to make best use of people and resources in the vicinity (Service Brokerage). They should be carer led and carer managed with the ability to employ their own staff and develop to meet the changing needs of carers in the locality rather than be tied to buildings and services, which are being provided ‘for carers rather than with carers’. (e.g. Romsey and District Carers Forum; New Forest Carers Forum; Carers Together Southampton).

Encouraging independent Carers Forums in each natural locality, linked and affiliated to a network organisation, could

- save money
- enable other funding resources to be accessed
- provide a better service
- stop confusion
- encourage partnership working in each locality
- produce accurate and comprehensive information for local citizens whichever role they find themselves in at any given time
- ensure that best use is made of limited resources.

Carers Together Annual Statement – August 2020

Carers Together issues an Annual Key Statement each year, sometimes more than once a year, to reflect the views of carers expressed during the previous and earlier years.

It is not a definitive statement but represents the continuing awareness and development of carers needs.

The Annual Statement was first issued in 2002 by Carers Together in Hampshire. It is updated regularly in response to the changing situation for carers.

The statements have all been made by carers during the last 20 years

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Carers Together is constituted to include carers in Hampshire Portsmouth and Southampton

A possible mapping plan for Carers Support is shown below.

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Carers Priorities 2020-21

No	Topic	Details	Action By	Date
1	Carers Assessments	• Carers Assessments – lateral thinking needed. • Timely – some carers are in crisis • Need agreed coproduced policy for Carers Assessments e.g. are carers going to be able to self-assess? If so how and what about the forms to use – will they be produced in coproduction. • Carers do not always want a joint assessment • Carers must be offered a separate carers assessments in a way that allows them to state their wishes without the cared for person present • Forms need to be sent out first, then when social worker comes people are prepared and know what to do • In Care Act - statutory • Online Carers Needs Checker needs to be available and simple for carers – easy to find		
2	Carers Preventative Services	• rather than crisis reaction • current reactive service does not assist with developing care solution or reducing problems • importance of regular contact with carers by social care agencies to avoid crisis situations developing – reviews should be positive not negative • Personal Contingency Planning (Say it Once) important to develop - could save time and money and encourage people to do more for themselves		
3	Carers Breaks AND Carers Respite	• Proportional • Equitable • Innovative • Point of Direct Contact • Discrimination between carers' breaks and services for clients causes concerns. • Carers Breaks need to be flexible, comprehensive, promoted, available (see SCIE document on Carers Breaks and Action Needed) • Reduction in carers' breaks is a current and future problem. • Respite care – choice? • What available – how flexible – how offered – part of carers assessment & personalisation or part of service users? • How Take a Break works and links together		
4	Carers Champions	• Health and Social Care • Should be created to promote and increase carers awareness and wider knowledge of Carers Issues		

5	Carers Complaints	• System needed to deal with issues and needs to look at learning from complaints • Need to get it right first time to reduce complaints • e.g. PALS in Health • Support from Peer Experts project is valued		
6	Carers Support	• What is the Policy? • Inconsistencies in application of Policies • GP Surgeries are variable • CQC Input? • Health & Care • Need flexible response e.g. respond to individual carers needs rather than menu of services (Strengths Based Action and Support)		
7	Carers Advocacy	• Peer Support is valued • Advocacy for carers – must recognised the need for peer advocacy and support. • LD Partnership has advocacy for people with a Learning Disability but not for carers. • Care Act Advocacy – but little or no inclusion of carers in the processes. • Independent peer advocacy for carers needed. • Carers may need advocacy because they have their own needs		
8	Coproduction	• Important to work together – health, social care, carers • Reduce silo working • Coproduction essential • Coproduction Strategy important – so it filters throughout the organisation • Service User Carer - fees and expenses – need to be consistent - Health & Social Care • Need to reflect on H&WB Priorities		
9	Finance Carers Financial Stability	• Carers need financial stability (support where necessary. • Financial issues. e.g. A mechanism should be devised to identify situations where carers face financial crisis following cease of carers allowance payments e.g. at state pension age • Means tested system should be devised for those carers who are in greatest need and/or who have little financial provision to support those they care for		
10	Finance Carers Benefits	• Conflict of benefits • Some misunderstanding of how benefits link • Help to complete applications, reconsiderations, tribunals should be accessed • Thinking about a bad day really important		

11	Finance Direct Payments for Carers	- Need better promotion - Better usage - Link to Take a Break money - Separate account		
12	Carers Awareness	- Carers - Professionals - Caring role - Include Young Carers		
13	Carers Rights	- Protect and publicise carers rights - Training in Carers Rights is available how can it be made more accessible		
14	Carers Representation	- How do we have proper representation for carers and with carers?		
15	Carers Strategy & Action Plan	- Local Carers Strategy - National Carers Strategy - Action Plan – essential for joint way forward – needs to be reviewed annually		
16	Carers Information	- Information about what is available for carers - Carers need timely, concise information. - It could be helpful to have a look at the many aspects of caring and somehow simplify the signposts e.g. short-term caring, lifelong caring, Young Carers (4 – 25), in the first instance so that carers are not searching for and wading through information that is not applicable to them. - Social Prescribers – carers template		
17	Care Packages	- Duty of AHC to review with empathy and include carers		
18	Care Plans	- Importance of having a personalised plan for carers - Link to Contingency Planning (Say it Once)		
19	Carers Centres	- Where - Co-design and co-use – so don't need a label - How run - Accessible		
20	Providers of services	- Good providers - Poor Providers - How reviewed? - How recorded? - How shared? - Put in touch with relatives of people in the Home		

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