



A life of my own

Knowsley Carers Strategy 2011-14

Are you looking after someone?

If you are then this could help you
and your family.

The Knowsley Carers' Strategy has been developed and
agreed by Knowsley People for Knowsley People.





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Executive summary

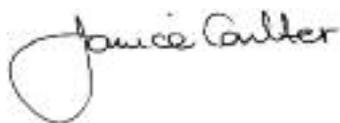
The Knowsley Carers Strategy is written by Knowsley People for Knowsley People.

It is accepted that, without the support of unpaid carers, health and care agencies would struggle to provide the level of care vulnerable people and children need to remain living in their own homes and community. Supporting people in their caring role is crucial to thriving communities and vital to promoting people's health and independence.

This Strategy is a working document which will plan and deliver services that reflect the new priorities for carers in Knowsley. It is a strategy for all carers including parents of disabled children, young people and sibling carers (under 18 years of age).

Through regular consultation and involvement on working groups and events, carers, ex-carers and their representatives have said what is important to them, and what they need to continue caring for their loved ones.

We would like to thank all those people and organisations who continue to support carers and who have helped to develop this strategy. We would like to acknowledge the considerable achievements, by many organisations in Knowsley, who provide respected and needed services to support carers in the Borough.



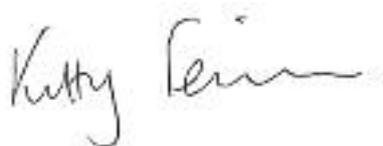
Jan Coulter
Director of Health and Social Care
Directorate of Wellbeing Services

We will continue to work together to commission and deliver quality support for carers and their families, of all ages, to ensure dignity and care when meeting people's needs.

This strategy builds on the existing good work by all the carers' partnerships and organisations and over the next three years we will continue to consult with carers and develop services and support to ensure access for those who need help.

Carers support groups will be encouraged to continue to grow and are vital in shaping the services that will be developed. We will revisit the aims of the strategy annually and feedback on the progress of the strategy action plan.

We are committed to working together to reach out to, and be alongside, Knowsley carers to provide them with the personalised support they need, and deserve, in carrying out their invaluable work.



Kitty Ferris
Service Director of Safeguarding and
Specialist Services
Directorate of Children and Family Services

Introduction and vision

‘If carers are to have the same opportunities as everyone else in society, and be able to have a life outside caring, we need to increase support and recognition for what they do. That means improving health and social care support, ensuring that carers are able to access education and leisure opportunities, and making sure that people with caring responsibilities have the chance to work flexibly so as to combine work with their caring roles.

‘For the many children and young people who support parents or other family members it means making sure that they are not providing unreasonable levels of care, and that they have the support they need to learn, to develop and to thrive.’

(Carers National Strategy: Carers at the Heart of 21st-Century Families and Communities. 2008)

The Government’s commitments are that by 2018:

- carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role;
- carers will be able to have a life of their own alongside their caring role;
- carers will be supported so that they are not forced into financial hardship by their caring role;
- carers will be supported to stay mentally and physically well and treated with dignity;
- children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive, to enjoy positive childhoods and to achieve against all the Every Child Matters outcomes.

A number of commitments have been made to carers and it is essential that these are turned into meaningful actions for carers in Knowsley. It is also essential that those actions are based on the experience, knowledge and aspirations of carers and their families.

In November 2010 the Coalition Government undertook a refresh to the National Strategy: Recognised, Valued and Supported: next steps for the Carers Strategy.

The refresh set out what the Government says should be the priorities for action over the next four-years. The aims remain much as before except for strengthening the focus on the needs of young carers and parents of disabled children, and, the benefits of a family-wide approach to supporting carers.

The following factors were identified as key priorities:

- Early Identification and recognition of carers and their needs.
- Realising and releasing people's potential.
- Carers having a life outside caring.
- Supporting carers to stay physically and mentally healthy.

Turning those priorities into real actions and services that support carers starts with carers themselves. It is crucial that we commit resources and spend money on services that are based on what carers know that they need. The aim of this strategy, therefore, is to set out clearly the main outcomes and priorities that Knowsley carers have identified as their own.

Our vision for this strategy and the way we work with carers is:

“To achieve a comprehensive, integrated and responsive approach to the needs and wishes of carers living in Knowsley, and to provide support, information and services to maximise their quality of life.”



Who are carers?

There has been a lot of discussion about the best way to define those people who provide unpaid care in the community. Carer is a term that many people do not like as they often see their role as mother, daughter, wife, sister, husband, son, brother, partner or neighbour and/or friend and not a ‘carer’.

But for the purpose of the strategy and in giving a clear understanding as to who the strategy is for then the definition used in this strategy is taken from the Princess Royal Trust for Carers.

‘A carer is someone of any age who provides unpaid support to family or friends who could not manage without this help. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.’

This definition includes parents of disabled children, young people and sibling carers (under 18 years of age).

Caring for people we love and value can be a rewarding experience and forms part of normal family and friendship relationships. The need to care for someone can happen at any time. It is not predictable and is something that most people do not plan for. However, it is something that most people will experience at some time in their lives. Anybody can become a carer as a result of a sudden event, such as an accident, or this may be a gradual process when someone’s physical or mental health slowly deteriorates.

Carers give practical, physical and emotional support to vulnerable people so that they can continue to live in their own home and communities. They help the person they care for to deal with problems caused by short or long term illness or disability, mental distress or problems resulting from alcohol or substance misuse.

The impact of providing care and support on the lives of carers manifests in many different ways, from the physical demands of caring, the emotional strain on relationships and because they worry excessively about the person they care for. Many carers have to organise their lives around the individual and the support they need. Caring responsibilities may vary over time and may be difficult to predict from day to day.

National picture and issues facing carers

A report from Carers UK, analysing the 2001 Census data, found that carers who provide high levels of care for sick or disabled relatives and friends are more than twice as likely to suffer from poor health compared to people without caring responsibilities. Analysis of the Census shows that nearly 21% of carers providing over 50 hours of care a week say they are in poor health compared to nearly 11% of the non-carer population.

It was also found that carers in younger age groups - i.e. 16 and up - are significantly more likely to suffer ill-health than non-carers of the same age. And, as carers become older, the evidence suggests that they are far more likely to be caring with ill-health - at a similar rate to their own age group. In other words, if they already have ill-health and take on caring responsibilities, this could have a further significant impact on their health.

A study based on analysis of the British Household Panel Survey 2009/10, also found that carers were more likely to report high levels of psychological distress, including anxiety, depression, loss of confidence and self-esteem.

The causes of carers' poor physical and mental ill health are identified by the A Carers Profile Report (DOH 2010) as being due to a lack of information, a lack of support (either the right kind or the right amount), worry about finances and the general stresses and strains of caring full-time with everyday life and isolation.

Local profile

In the 2001 Census, 17,360 Knowsley residents described themselves as unpaid carers. This represents 11.5% of the Borough's population and is slightly higher than the national average of 10%. Three out of 10 Knowsley carers reported providing more than 50 hours of unpaid care each week. The national figure is two out of 10.

The extensive Place Survey carried out in 2008-09 used additional questions to further develop the profile of caring in Knowsley.

- 231 people (17% of the responses) said they provided care for somebody
- 53% of the 231 said they were a main carer
- 76% said they did not receive any formal services
- 52% said they provide 30+ hours of care per week
- If 17% of Knowsley's adult population is a carer as identified in the survey this would equate to 19582 carers
- If 53% were the main carer this would equate to 10378 carers
- 76% of these did not receive services this would equate to 7888 potential carers without a service
- 52% of these carers providing 30+ hours of care per week could equate to 4102 carers providing high level support

From this survey it could be argued that 17% and not 11.5% of adult Knowsley residents are carers and so a far higher number than previous estimated.



Developing the strategy

The journey started in August 2010 when representatives from a range of organisations of and for carers and those organisations who support and come into contact with carers were invited to form the Carer Engagement Group (CEG). The purpose of the group was to be the lead on deciding how to make the strategy a reality and how to involve and consult with as many carers as possible.

The officers working on the strategy had a plan for getting carers views but the CEG disagreed and decided that the best way to get carers views and experiences would be to have special events where carers and others from social, health and other relevant services would come together and agree what should go into the strategy.

The first event was on the 8th September 2010. The CEG decided that this would be an event for carers and former carers only and 45 people came and gave their views on what areas of their life were most affected by being a carer.

On the 8th October 2010 a group of young carers got together with staff from the Knowsley Young Carers Project and talked about the important things in their life and the impact of having to care for family members. The young people had a lot of ideas and suggestions on how their lives could be better.

On the 21st October and 25th November almost 70 carers, former carers and staff from social and health services started to work in small groups to look at the five main themes that had been identified at the first carers' event, they were: A Life Outside of Caring; Carers Physical and Emotional

Health and Wellbeing; Access to the Right Information: Carers being Involved and Informed and Carers being Treated as Partners.

Carers told us what the outcomes were that they wanted from each of those themes and the barriers they experienced and felt were in place that stopped them achieving them. Finally a lot of information was gathered about possible ways to get over those barriers and to develop services and support that would work for them.

The final event, on the 18th January 2011 had people coming together and having the chance to discuss all the themes and outcomes and to agree that these were the priorities for them and what should go into the Carers' Strategy.

Many of the people who came to these events had never been involved in any form of formal consultation event before. Comments from the evaluation forms completed after each event showed that the majority had a positive experience, had learnt new information and felt that they had participated fully in the event.

As a result of all the hard work carried out by those who attended the events, the CEG,

those who acted as facilitators for the work groups and staff from social and health services a clear set of outcomes were identified covering every aspect of people's lives and their caring experience.

To try to make sure that the outcomes were right, during February and March 2011 members of the CEG provided carers with a short survey that gave them the chance to say if they agreed with the outcomes and what were their top five priorities that they wanted to see happen first. 88 people responded to the survey which was also available online to Knowsley Council and PCT staff through 'In the Know'.

An event was also organised by the Knowsley Older People's Voice and LINK to get a group of carers together to seek their views and we asked the Knowsley CVS to find out from parents of children with

disabilities if they agreed with the outcomes. At the end of this stage of consultation the top five outcomes had been identified for adult and young carers.

Between March and August 2011 the CEG and themed working groups will be working to develop and produce a set of detailed action plans for each of the identified outcomes, starting with the priority outcomes. These will be shared and consulted with as many carers as possible.

The full Action Plans will be published in September 2011.



Reviewing the strategy

The strategy will remain under continuous review by the Carers Partnership Board and the associated implementation groups commissioned by the Board.

The development of the Carers Partnership Board provides a forum for Carers to work alongside Commissioners and Providers to develop future services for Carers. Six representatives elected via the CEG will sit on the Carers Partnership Board alongside an equal number of representatives from Knowsley Health and Wellbeing / Children's Services.

The CEG are central to the work of the Carers Partnership Board as they will provide the opportunities to communicate the work of the Board to Knowsley Carers:

CEG Members

- Princess Royal Trust Knowsley Carers Centre
- Alzheimers Society
- Knowsley Parents Forum
- Knowsley Older Peoples Voice
- Knowsley LINK's
- Knowsley Young Carers
- KPAC
- Knowsley Pensioners Advocacy and Information Service
- Caring Companions (Kirkby and Prescot)
- Knowsley Disability Concern
- Crossroads Care Knowsley
- Age UK Knowsley
- Making Space
- Partnership Officer representing the Mental Health, Physical Disability and Learning Disability Partnership Boards

Every 3 months the CEG will invite people to attend an event where the progress of the agreed strategy actions will be presented and discussed. People will have the opportunity to express their views on the progress made and these views will be fed back into the Carers Partnership Board.

In addition, the Knowsley MBC Health and Wellbeing Scrutiny Committee chose Carers Support to be an area that they wanted to investigate and review. They made a number of recommendations based on the evidence and information they found and these were agreed through Cabinet Committee in April 2011. Throughout the following 12 months the progress of those recommendations will be monitored by the Scrutiny Committee through the work of the Carers Partnership Board.

Links to other Knowsley strategies

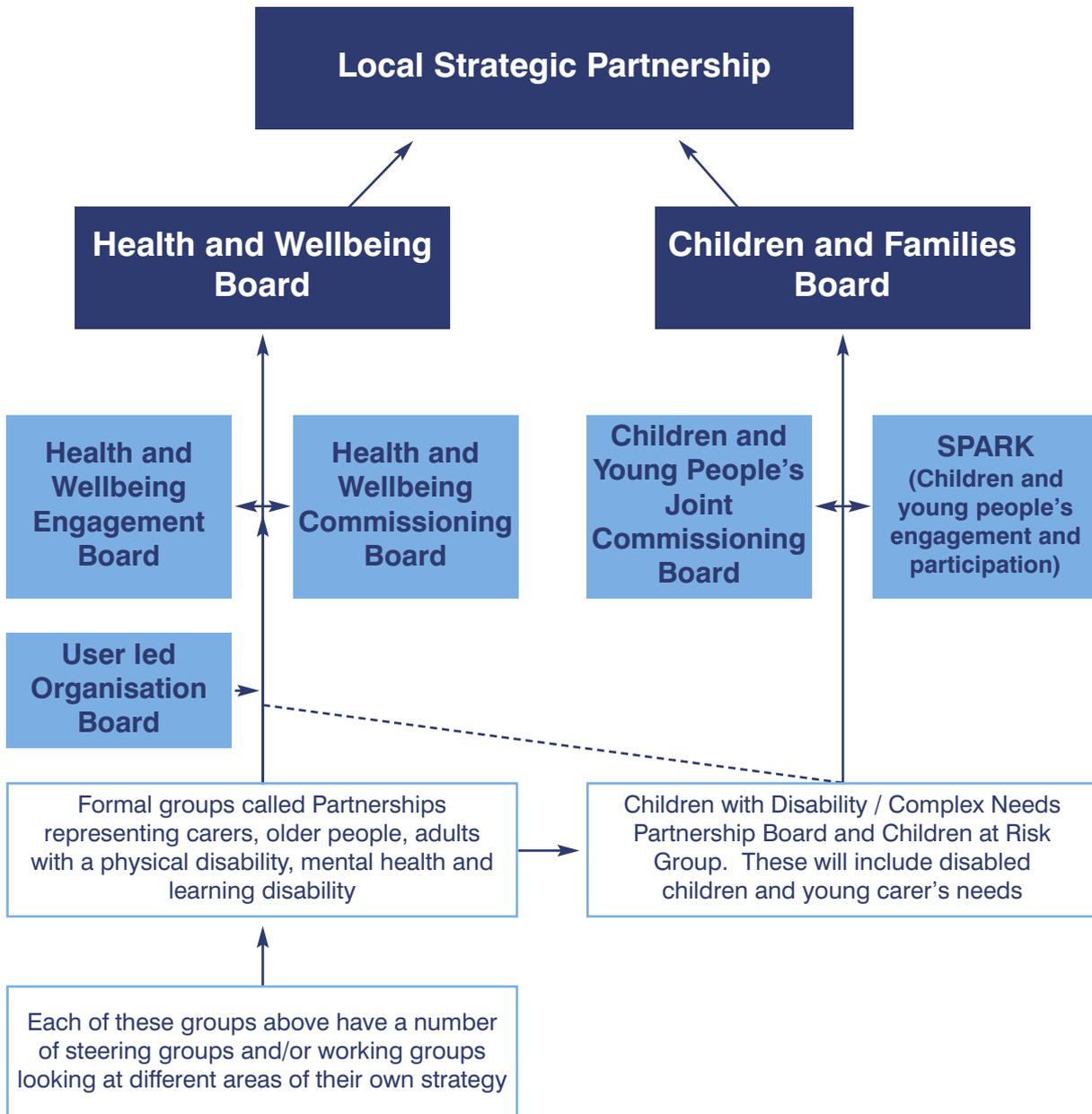
The issues that affect carers do not fit into a neat box and can not be dealt with by one service or organisation. Carers support people who have long term illness and disability, learning disabilities, mental illness, alcohol and substance misuse. They can be 9 or 90 years old, caring full time, part-time, working, retired or in education. The point is that caring can affect all of us at any time in our lives and so this strategy must link closely with the other children and adult strategies and plans.

These include the Older People's Strategy, the Dementia Strategy, the End of Life Strategy, the Mental Health Strategy, Knowsley Children and Young People's Strategic Plan, the Memorandum of Understanding: Working Together to Support Young Carers.

We will work together with children's and adult's services, management and staff to try to make sure that we work together across all these strategies to make sure that the needs of carers are raised and understood and acted on.



The map below shows how we will make sure that important issues, affecting adults and children, raised by the Carer's Partnership Board are past onto the decision makers who represent the Council, GP Commissioning Consortiums and Health Services.



Priority outcomes

There is much to do to put what people need into practice and they cannot all be achieved at the same time. The information below sets out the plan of intention based on the outcomes that carers told us they want to see happen first. Those priority outcomes are highlighted and point out if they are a priority for Adults or Young Carers.

Theme

A Life Outside of Caring

- 1. Carers want the opportunity for regular personalised breaks suited to their individual situation. They need to spend quality time for themselves on something other than caring and with their family and friends.**

Adults and Young Carers Priority

To be meaningful to carers the ways to achieve the outcome needs to take into account the following issues:

- 'time for me' Recharge: Relief: Relax
- It needs to be a priority: better funded: need more information on how to get it: has got to be based on the individual needs of carer. They need to be better planned and agreed in advance
- 'there needs to be choice'
- Need for breaks that meets both the needs of carers and their cared for
- Having breaks and holidays together
- Having a confidence in the placement or organisation providing care
- That avoids crisis and emergencies situations

- 2. Carers want to have the opportunities to take part in normal family life, social activities, leisure, education and to be part of their community.**

Young Carers Priority

To be meaningful to carers the ways to achieve the outcome needs to take into account the following issues:

- Access to leisure and exercise facilities for carers is essential to ensure carers continuing ability in their caring role

- 3. Carers want support to be able to stay in education or to stay in/get a job.**

Young Carers Priority

To be meaningful to carers the ways to achieve the outcome needs to take into account the following issues:

- Carer friendly employment policies
- Flexible working options
- Advice specifically for carers around employment opportunities

4. Carers need to have a clear plan for responding to emergencies where the carer is unable to provide support on a temporary basis.
Adult Carers Priority

To be meaningful to carers the ways to achieve the outcome needs to take into account the following issues:

- Needs regular reviewing and should be agreed between cared for and carer
- Emergency planning should be raised/addressed in care plan/carers assessments - they need to link up

Theme

Carers physical, mental and emotional health and wellbeing

5. Carers want to be kept fully informed and involved when the person they care for is in hospital and fully involved in hospital discharge.
Young Carers Priority

To be meaningful to carers the ways to achieve the outcome needs to take into account the following issues:

- Better communication, be involved in planning, better support from community health, be told what is happening and for medical staff not to take things for granted
- Carers should be involved at every stage of the hospital discharge process from diagnosis/treatment stage
- Recognition of carer's knowledge about the person they care for and their circumstances

6. Carers want to have access to community health services that are flexible and understand and meet their needs.
Adult Carers Priority

To be meaningful to carers the ways to achieve the outcome needs to take into account the following issues:

- To be taken seriously by medical staff, be seen as an authority for the person I care for, to be listened to, be respected - not ignored
- Better communication between agencies, doctors, health groups and local authority
- Respect and dignity of the carer and person they support

7. Carers want to have access to GP services that are more flexible and understand and meet their needs.
Adult Carers Priority

To be meaningful to carers the ways to achieve the outcome needs to take into account the following issues:

- GPs to better understand the carer and their health needs
- Need for a more personal approach (especially in GP practices) we are people not numbers
- Recognition of carers' knowledge about the person they care for and their circumstances

8. Carers want to be offered the opportunity to develop their skills and knowledge that will help them in their caring role.

To be meaningful to carers the ways to achieve the outcome needs to take into account the following issues:

- Make use of carers' skills/knowledge/experience when developing training.
- Training package - Caring with confidence has lost central government funding - this was much valued, could we somehow re-establish this locally?
- Training around legal issues

9. Carers want to have the chance to talk about their experiences and to be offered the emotional support they need.
Young Carers Priority

- Carers stress level assessed and monitored. Availability and access to psychology support/counselling to discuss feelings/listening ear/support groups

10. Carers should not be financially disadvantaged because of their caring role.
Adult Carers Priority

- Benefits advice (and other financial awareness training)

Theme Access to information

11. Carers want to be able to access quality and consistent information when they need it, in an appropriate format and for information to be accessible.

To be meaningful to carers the ways to achieve the outcome needs to take into account the following issues:

- To develop an information hub, including a website that signposts carers to:
 - Employment
 - Financial Advice and Benefits
 - Leisure service
 - Education advice for carers, identifying opportunities available
- Carers can have support from independent advocacy to help them
- The people who work with carers need to have knowledge and access to appropriate information around carers and general universal services

Theme Carers involvement

12. To strengthen and develop meaningful ways for carers to be consulted and as involved as they wish in the planning, commissioning and monitoring of carers' services.

To be meaningful to carers the ways to achieve the outcome needs to take into account the following issues:

- Listened to and recognises that carers are the experts
- Need a strong voice in Knowsley - more commitment
- 'Listen to me' and 'listen to what I say'
- I want to be involved and have my voice heard
- I want to be listened to. I want to influence decisions
- I want to know about changes going on
- Carers are involved in the writing and implementing the strategy and feel valued

Theme

Carers - treated as partners

13. Carers want to be fully involved in the assessment of the person they support and be treated as partners in the development of support plans.

Adult Carers Priority

To be meaningful to carers the ways to achieve the outcome needs to take into account the following issues:

- Carers want to have access to a carers' assessment that reflects their needs and supports a life outside of caring
- They want to be involved in the decision making process about their lives which leads to more informed assessments and better monitoring of any services provided
- Carers want to be offered a separate assessment which addresses issues that affect the whole family and that is carried out in the setting of their choice
- Being told about carers assessments, the assessments being treated seriously and worth doing
- Have a carer's assessment that is meaningful to their lives and needs
- Treated as an equal, my opinion being valued, being listened to
- Having staff that are good listeners, understand the effects on the whole family, have a good knowledge of what's available for me, being on my side

Theme

Young carers

- To support young carers through the transition from childhood to adulthood and the changes in formal social and health services
- To support young carers to gain access to the information and advice they need in the right format and place
- To identify young carers and offer them the support and advice that they need
- That young carers will be protected from inappropriate caring and have the support they need to learn, develop and thrive and to enjoy positive childhood



