

× s Department of Health



Community Nursing Programme: Professional pathway for community nurses

Supporting the health and wellbeing of adult carers

Context and Rationale

Maximising opportunities through **Compassion in Practice**

Priority action and suggestions for delivery

Acknowledgements, Supporting Policy and Evidence







Context and rationale

This pathway sets out the key messages for community nursing services to empower and to meet the needs of adult carers. It sets our aspirations for the community nursing contribution to provide improved and seamless support to the health and wellbeing of carers. This pathway is guidance to support community nurses to work more collaboratively with other key professionals and partners to deliver improved quality of life and health outcomes for both the carer and the people they care for. The pathway focusses on the district nurse and general practice nurse contribution; however the principles are transferable to other professionals within community settings. The pathway builds on good practice and evidence drawn from a range of professional and partner agencies including: Allied Health Professionals, GPs, social care, practice nurses and third sector agencies. Local service providers will be at different points of development and can use the pathway to benchmark their current position and to drive improvements.

Community nursing services cannot support carers in isolation, and this pathway aims to ensure community nurses can identify, assess and act on issues facing carers and work effectively with other agencies to improve support. This pathway focusses on the health and wellbeing needs of carers; the care of patients is addressed in other documents. The pathway outlines the challenges community nursing services face and opportunities for improvements in support that can be achieved through an integrated approach.

Carers can experience diminished quality of life and poorer health outcomes. This pathway shows how nurses can contribute to overcoming these challenges and contribute to individual and population improvement. The proposed actions outlined in this pathway require the skills, knowledge and leadership from district nurses and general practice nurses. Both professional groups are skilled in working effectively with partner organisations and stakeholders. All professionals need to respect carers as expert partners in care.

The 2011 Census showed that there are now 5.8 million carers in England and Wales. Over a third of carers were providing 20 hours or more of care a week in 2011, Since 2001, the number of people caring for 50 hours or more a week has increased by 270,000, which represents a 25% increase. The results of the census demonstrated that the general health of carers deteriorates incrementally with increasing hours of care provided. People caring for 50 hours or more a week were more than twice as likely as those not providing care to report their general health as "not good".

Learning from the evidence

The overarching rationale for the pathway is to support consistent, seamless support and care for carers. Enhanced partnership working will improve quality outcomes for both patients and carers. Underpinning this is:

- 1. Currently 5.8 million people (10% of the population in England and Wales) identify themselves as unpaid carers, caring for someone with an illness or disability.
- 2. Over a third of the population of England and Wales (37 per cent, 2.1 million) provide 20 or more hours of care a week.
- 3. An estimated turnover of around 2 million carers per year
- 4. Evidence from the community workforce illustrates that there is currently no single profession or organisation that can ensure the best outcomes for carers. This reinforces the need for a partnership pathway. See Health Visiting and School Nursing Programmes: supporting implementation of the new service model: No 2: School nursing and health visiting partnership - pathways for supporting children and families, Department of Health, 2012
- 5. The specialist public health and specialist community nurses with the skills and expertise working as knowledgeable supporters for carers health, in partnership with other agencies.
- 6. A clearer understanding and evidence base of the impact of early intervention and the economic savings that can be achieved through the provision of early help and therapeutic support through leadership, joint working and appropriate referral.
- 7. A Literature Review revealed that carers need:
 - An awareness of nursing-based technical information, including fundamental nursing care and medicines management
 - Education on providing emotional support for the people they care for
 - Signposting to assist in navigating services and identifying other support services they may need
 - A family approach to care from community nurses, which includes the assessment of their own physical and emotional needs
- 8. There is evidence of growing numbers of older people from minority ethnic groups in need of care and being cared for by family members, often with little external support. See Dementia does not discriminate: The experiences of black, Asian and ethnic minority communities, House of Commons all-party group on dementia, 2013

Figure 1

District Nurses, General Practice Nurses and wider community nurses can support carers at a number of levels, from emotional support to working with partners to provide specialist support through enhanced approaches.



Enhancing Support for Carers

Ensuring the best possible support for carers means addressing service challenges and identifying solution focussed approaches. Local service configuration, delivery and resourcing needs to be supported through local partnership working between health, social care and voluntary organisations, commissioners as part of the adoption of the partnership pathway principles. This pathway is a guide that can be adapted to ensure the needs of carers are met, taking into account local health priorities, health needs and resource deployment. Professionals need to work together to develop an understanding of each other's roles to ensure the early identification of need and support for carers. This will maintain the health and wellbeing of carers and the people they care for. The use of a partnership pathway will support effective delivery and provide solutions to address local challenges including:

- Providing strategic leadership: Developing local ownership and strategic support to ensure there is understanding of the impact of a caring role on carers' health and wellbeing;
- Improving partnership working: Building strong positive local relationships and ensuring there are formalised liaison and referral processes to provide seamless support and develop closer working relationships with wider partners, including housing, adult social care and voluntary sector organisations;
- **Supporting the workforce:** Developing joint training and peer support http://gni.org.uk/for nurses/supporting carers/about the carers project
- Maximising resources: Promoting best practice to support delivery and improved signposting between professions;
- Enhancing improved communication: Developing local processes to improve transfer and sharing of information between health and social care;
- Standardisation of procedures within professional boundaries whilst maintaining confidentiality: Sharing information appropriately' between health and social services to support carers' needs;
- Supporting seamless access: Providing clarity of roles, responsibilities and referral systems to ensure a continuum of support as carers needs change;
- Making Every Contact Count: Optimising opportunities and personalising care;
- Using the evidence: Supporting identification through enhanced knowledge of what works and using the evidence to underpin delivery of effective support.

Key Messages from Carers

During the development of this pathway adult carers shared their views and key messages for professionals.

- We want to keep a normal home routine
- Take time to speak to our families and carers to find out our needs
- Help us with our 'wellbeing' and mental health
- · Help us to stay in our home with as much support as is necessary
- Tell us what carer breaks and respite are available to us
- Help us to identify triggers to anticipate and prevent crises
- Help us to get support to manage care alongside paid employment/childcare responsibilities
- · Recognise increasing frailty of older carers/likelihood of spouses undertaking mutual caring roles
- Support young carers with their transition role to adult carers.

Professionals responding to the messages from carers

The development of robust support for carers' health and wellbeing needs through more effective identification and monitoring and collaborative working with key professionals, partner organisations and professional groups, including GPs, General practice Nurses, Allied Health Professionals, voluntary sector and social care is essential. Community nurses need to:

- Identify and review health and wellbeing needs for carers (linking to Local Authority colleagues).
- Identify carers with additional needs and provide clearer contact points to professional and expert service providers.
- Support the carer to manage care alongside paid employment/childcare responsibilities.
- Review and evaluate formal/informal support provided in line with the carers' ongoing needs.
- Support health and wellbeing needs of ageing carers' through more effective identification and monitoring through collaborative working with key professionals, partner organisations, professional groups, GPs, social care and voluntary sector
- Assess and review health and wellbeing needs, recognising increasing frailty (link to existing assessments) and deliver appropriate support packages.
- Recognising the likelihood of spouses and partners taking mutual caring roles.
- Review and evaluate formal/informal support provided in line with the ageing carers' ongoing needs and provide support for older carers to navigate the system.
- Use assisted technology and I.T. to support carers, e.g. internet/Skype/face time/telehealth support
- Identify specific cultural needs of people from minority ethnic groups and work with BME voluntary sector to identify best practice in addressing them

Maximising opportunities through Compassion in Practice

Compassion in Practice: Nursing, Midwifery and Care Staff: Our Vision and Strategy provides a framework which can help identify where there are opportunities for District Nurses, General Practice Nurses and the wider community nursing services to improve support for carers' health and wellbeing.

Figure 2 illustrates the inter-connectivity between Compassion in Practice and the district nurse service offer.

Below describes the core values and skills community nurses should embrace to ensure support for the health and wellbeing of carers.

Care

- Support for carers to care effectively, by providing relevant and timely information, advice and support
- Increase equality of services and the quality of support for carers, to maintain health and wellbeing
- Optimise and maintain physical health and wellbeing of carers.
- Deliver continuous and coordinated care to support carers to care effectively across different disciplines and sectors
- Ensure quality of care and support through robust continuous clinical audit in clinical practice.
- Utilise clinical guidelines and evidence-based practice
- Support the specific needs of BME groups
- Appreciate high expectations of informal care in BME families, additional pressures associated with gender roles and socioeconomic circumstances.

Communication

- Ensure carers are given appropriate information, training and support so that quality care is maintained when professionals are not present
- Improve multidisciplinary communication, teamwork and planning to support early identification and signposting and referral of carers including building strong relationships with carer organisation to provide integrated support
- Ensure the alignment of communication between health (particularly GPs, general practice nurses and district nurses), social care and partner agencies with third sector and in some cases with carers as well.
- Improve the sharing of information to improve seamless support for carers
- Ensure information is available in relevant community languages and multi-media approaches.
- Recognise language differences and potential impact on care.

Compassion

- Empowerment for carers, recognising and utilising the skills and expertise of carers as equal partners in care
- Listen to carers, support their needs and their caring role
- Build on what works to support carers and the people they care for, to maintain health outcomes.
- Effective liaison with other health and social care professionals to ensure needs are met with regard to family members i.e. general practice nurses and district nurses providing seamless support
- Work in partnership with carers to get a better understanding of the care and compassion issues that affect them.

Courage

- Advocate for carers needs to enable them to support the patient/client
- Challenge decisions and support acknowledgements when things are not going well
- Recognise carers as experts in care and provide support to avoid crisis or risk to carers health and wellbeing
- Champion and highlight good practice and also be able to challenge areas of practice requiring development.
- Act as a local champion for carers needs and use negotiation and influencing skills to instigate change
- Ensure positive and professional role models for patients and carers
- Recognise limitations of cultural knowledge and competence and seek to help learn from families of formal learning
- Provide advocacy for translation and dietary needs.

Figure 2



Competence

- Ensure right person, right skills, right time all of the time • Ensure care is provided by experienced and knowledgeable practitioners, with the skills to communicate effectively to patients, carers and their families.
- Improve use of skill mix and specialist roles.
- professional groups.
- Improve access to relevant and timely training and expert support networks by clearer signposting and availability of information • Acknowledge and endeavour to incorporate cultural beliefs and values about ageing and illness.

Commitment

- Provide on-going support to ensure carers' needs are met
- Use opportunities to consistently promote **Carers** needs to wider multi-disciplinary team
- Improve patient and carer satisfaction.
- Support innovative quality initiatives in practice and identify areas for development within the support for carers recognising and sharing good practice
- of working
- Ensure transparency for a better patient and carer experience • Support change management and embrace new ways of working to improve support for carers
- - additional support.



- Harness partnership skills and expertise working within the
 - changing agenda, recognising core values of adult services.
- Increase peer support and inter-agency training between

- Comment on and enhance current practice and embrace new ways
- Improve patient and carer satisfaction, paying particular attention to those whose culture, language or social circumstances require

Priority actions and suggestions for delivery

The 6 Actions Areas within Compassion in Practice provide a framework on which to identify and support new ways of working to support carers' needs and promote the need for:

- Empowering carers and ensuring support systems to help carers to live their own life as well as recognising the carer as the expert in providing care and support for another person.
- Family centred approaches to care, support and decision making processes to focus on the health and wellbeing needs of the carer.
- Partnership working within the changing health and social care agenda, recognising core values of supporting carers.
- Collaborative-working to empower and optimise health and wellbeing of carers.
- Recognition that carers often know the person they look after best and are experts in their care
- The use of informal support networks for carers e.g. befriending, peer support and carer organisations http://www.carers.org/ http://www.carersuk.org/

Maximising health and wellbeing: helping to keep people independent

Empowering carers and supporting their health and wellbeing

The importance of communication is evident throughout this pathway. It is essential that carers are offered the appropriate information at the right time and pace for them. This is in itself a challenge.

- Recognition that every individual carer has unique and specific needs and requires sensitive assessment to enable identification of carer status, to enable appropriate and timely signposting for support/intervention.
- Use an local assessment tool which forms part of the initial assessment for completion by professionals

Suggestions for delivery:

- Acknowledge the need for information can change as circumstances change e.g. deterioration of condition/end of life
- Implement an approach towards identification and assessment of carers, using an assessment identification tool, to include collaborative approaches with prompts for signposting to key professional organisations
- Ensure feedback loops to GP and General Practice teams on carer health outcomes
- Use a local assessment tool which takes account of cultural/ religious factors and forms part of the initial assessment for completion by professionals

Building and strengthening leadership

Supporting effective leadership and opportunities for staff to develop new skills will support staff to be confident and competent, this will enhance collaboration

Suggestions for delivery:

- Provide new opportunities for learning and to develop leadership skills
- Support cross-agency collaboration and support for carers
- Encourage new ways of working to support the needs of carers
- Provide regular supervision and training opportunities to encourage personal development

Delivering care and measuring impact

The impact of care and support needs to be clearly defined and measured locally. All care and support should be under-pinned by evidence.

Suggestions for delivery:

- Develop a local Carer Assessment Identification Tool to prompt appropriate assessment, identification and ongoing review to enable support for carers.
- Provide an audit trail of documented needs/outcome to aid decision making.
- Develop robust systems to measure impact and outcomes
- Develop multi-agency networks to support carers
- Monitor unmet needs of carers and the cared for
- Identify when caring impacts on personal health and wellbeing and ensure access to support
- Use the knowledge, expertise and reach of BME voluntary sector to identify need, develop/deliver support and evaluate services

Supporting a positive staff experience

Role definition

Clarification regarding roles and responsibilities and processes will ensure effective use of resources and skills to assist carers and the people they care for.

Suggestions for delivery:

- Ensure appropriate and meaningful staff support and training
- Promote effective use of informal networks to support community nurses to develop and expand skills
- Provide training for community nurses, particularly District Nurses and General Practice Nurses
- Provide on-going awareness training/Assessment tool

Right people, right skills, right place

Partnership working

Collaborative and integrated working with skilled staff promotes understanding of the contributions the health and social care team will support carers to undertake their caring role.

Suggestions for delivery:

- key professionals and organisations
- Nursing and District Nursing services
- pertinent to local communities

Working with people to provide a positive experience

Empowering carers and ensuring carers have access to information/advice to ensure their own health and wellbeing needs are met. This may include:

Suggestions for delivery:

- packages
- patient stories
- into account.

 Inter-professional bite sized key training packages for 'lead professionals' - how to use local assessment, communication and negotiation skills.

• Training to include collaborative approaches with prompts for signposting to

http://gni.org.uk/for nurses/supporting carers/about the carers project

Identify champions to raise awareness of carers' needs with General Practice

 Ensure further development of 'Carer Champion' roles across the sectors • Ensure training to include cultural awareness, sensitivity and competence

Support to pursue education, recreation and/or paid employment

• Support to navigate the system(s) to identify relevant and key stakeholders to broker support arrangements and ensure positive outcomes

Provide emotional support and effective listening to identify and agree support

• Early identification and signposting and referral of carers to optimise and maintain physical health and wellbeing and financial independence of carers.

• Utilise appropriate patient and carer feedback tools and learn from carer and

 Identify the needs of carers within the family context, work and education context, ensuring that design and delivery of these services takes these needs

Acknowledgements, Supporting Policy and Evidence

Supporting policy, evidence and resources

- Carers Strategy
- Supporting Carers: an action guide for general practitioners and their teams (second edition), Royal College of GPs and the Princess Royal Trust for Carers (now Carers Trust) http://professionals.carers.org/health/articles/carers-inpractice-rcgp,1792,PR.html
- Recognised, valued and supported, Next Steps for the Carers Strategy, Department of Health. 2010 http://www.dh.gov.uk/prod consum dh/groups/ dh digitalassets/@dh/@en/documents/digitalasset/dh 122393.pdf
- New Approaches to Supporting Carers' Health and Well-being: Evidence from the National Carers Strategy Demonstrator Sites programme http://www.sociology.leeds.ac.uk/circle/news/new-approaches.php
- Carers Trust Carers Hub http://www.carershub.org/
- Skills for Care/Skills for Health training framework Carers matter everybody's business http://www.skillsforcare.org.uk/carers/
- Best practice, better practices A new deal for carers in primary carehttp:// www.carers.org/sites/default/files/best-practice-better-practices-1709.pdf
- Carers' health survey http://static.carers.org/files/carershealthsurvey-12.pdf
- Carer quality of life tool http://professionals.carers.org/health/articles/carerguality-of-life-tool-launches,7010,PR.html
- Catherine Walshe, Sheila Payne and Karen Luker (2012) Caring for the carers? An observational study of the role of the district nurse in palliative care, BMJ Support Palliative Care 2012; 2:A39 doi:10.1136/ bmjspcare-2012-000196.113
- 2011 Census. Office for National Statistics http://www.ons.gov.uk/ons/guide-method/census/2011/index.html
- Care in Local Communities: a new vision and model for district nursing, Department of Health, NHS Commissioning Board and the Queen's Nursing Institute, 2013 http://media.dh.gov.uk/network/387/files/2013/01/District-Nursing-Vision FINAL 6.pdf
- No-one Alone http://www.noonealone.org.uk/families-and-carers/
- Dementia does not discriminate: The experiences of black, Asian and ethnic minority communities, House of Commons all-party group on dementia, 2013
- Making Every Contact Count
- The Queen's Nursing Institute, About the Carers Project

Acknowledgements

The pathway was developed collaboratively and in partnership with representatives drawn from the nursing profession, a range of stakeholders across the NHS and other partner organisations. Wider consultation has been facilitated through the professional organisations. Thanks are extended to all contributors, specifically the following:

Members of the Task and Finish Group

Ben Bowers

Suzie Clements

Community Cancer Nurse Specialist, Queen's and Community Health Nurse Cambridgeshire Community Services NHS Trust

Education Lead, Hospital Services Chair, Practice Nurse Association, Royal Collect of Nursing

Siobhan Gregory

Director of Quality and **Clinical Excellence** Hounslow and Richmond Community Healthcare NHS Trust

Anne Pearson

BSc(Hons) QN

Crystal Oldman

Chief Executive The Queens Nursing Institute

Sally Sprung

Programme Lead for **District Nursing Liverpool** John Moore's University

Teresa Wood **Community Paediatric** Matron. Children with **Complex Needs Team** Milton Kevnes Community Health Services

Secretariat:

Wendy Nicholson, Professional Officer Nursing, Department of Health Elaine Edgar, Head of Policy, Carers, Department of Health Fiona Hill, PA to Professional Officer - Nursing, Department of Health

Julia Ellis Development Manager

(Primary Care and Community Reach) Carers Trust Michelle Laing

Professional Lead for

Adult Nursing Liverpool

John Moore's University

Marie Hudson RGN

District Nurse Team Leader Peninsula Community Health CIC

Alison Raw

Allied Health Professional Officer Department of Health

Practice Development Manager The Queen's Nursing Institute