



# Carer Support Pathway in End of Life Care

A report based on a six month pilot project to identify needs and recommend solutions for supporting carers during the 'final year of life' phase of a caring role

Delivered by The Carers' Resource

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The Carers Resource

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# Carer Support Pathway in End of Life Care

## CONTEXT

*'How people die remains in the memory of those who live on'*  
Dame Cicely Saunders, Founder of the Modern Hospice Movement

*The End of Life Care Strategy (July 2008)*

*Chapter 5: Support for carers and families*

Carers and family members of a person who is approaching the end of life can have a vital role in enabling that person to die in the place of their choice. They also have their own needs. Many carers willingly take on the role of looking after someone close to them who is nearing the end of life. However, the physical, psychological, social, financial and spiritual consequences of doing so need to be taken into account.”<sup>1</sup>

## PROJECT DESCRIPTION

The Carers' Resource secured six months' funding through Yorkshire and the Humber Improvement Partnership's Carers' Innovation Fund to identify existing provision in carer support services, identify gaps and create a pathway showing when, how and where carer support is and/or should be offered.

In partnership with existing health and social care teams working on the end of life pathways in Bradford, Carers' Resource piloted and evaluated provision of specialist carers services. The project looked at providing specialist support for carers of those nearing the end of life both in hospital and at home.

## PROJECT AIMS

- *Look at existing specialist carer support services and gaps in provision at the End of Life*
- *Explore ways of embedding carer support into secondary and community care services with an End of Life focus*
- *Build partnerships with health and social care professionals working in this field to share expertise*
- *Begin to develop a carer pathway to ensure the appropriate type of support is offered at the best time(s) and in the best ways/locations*

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<sup>1</sup> **End of Life Care Strategy** Promoting high quality care for all adults at the end of life.' Department of Health Publication July 2008

## *PROJECT DELIVERY*

- Approaches were made to various teams – Hospital Palliative Care, Hospital Discharge and Care of the Elderly wards within Bradford Royal Infirmary (BRI) and Airedale General Hospitals (AGH). Additionally we spoke to local hospices including Marie Curie Leeds Road in Bradford plus the Community Teams and also some specialist clinics including the Motor Neurone Disease (MND) clinic from Airedale General Hospital to secure placement opportunities for our Carer Support Officers (CSO).
- We allocated the twenty five hours of carer support time funded through the project to cover Multi-Disciplinary Team (MDT) meetings within palliative care and discharge at BRI and palliative care at AGH. This was to ensure early identification and referrals could be made directly into the service and followed up later. Additionally it gave the CSO chance to feedback on previous referrals direct to the referrer.
- We also allocated time for a combination of collecting referrals and direct carer support 'in situ' by placing a CSO onto the Care of the Elderly wards during visiting time and throughout the MND clinics (held six weekly)
- One of the CSOs delivering the project has a community outreach background, is familiar with a number of BME communities and can offer support in a variety of community languages. We felt this was essential to reflect the diversity of the client base we would be supporting.
- When a referral was received we made an initial contact to see if the carer wanted support at that time. For those who did, this varied from an information pack or more complex tailored information enquiries through to intensive one to one carer support undertaken either at the carer's own home, at the hospital or clinic, at our office or at another 'safe venue' chosen by the carer.
- The main aspects of support required involved listening and emotional support, financial and benefits guidance/applications, work related advice and signposting or referrals for further support such as assessments, equipment or breaks.
- Once the project had been completed we undertook feedback work with some of the carers and professionals involved. We wanted to establish whether the support provision through the project was appropriate. We also wished to ascertain for future provision whether it was timely, or how this could be improved. This helped to guide the pathway creation.

## OUTSTANDING SUCCESSES

Given the very short timescale, the various barriers encountered (see section Barriers and Areas for Improvement) and the limited amount of funding, the quantitative data was particularly pleasing as the project was able to offer substantial support to 55 carers and in addition over 40 carers received *ad hoc*, piecemeal help on the wards but did not take up the offer of further 'formal' support at this time.

From a qualitative angle we have evidence to show the project was successful in a number of ways including:

### **'On The Spot'**

One of the major areas seen as particularly valuable by carers was having the support and specialists available immediately and 'on the spot'. Carers struggle to find time to accept help for themselves but always make time for appointments or visiting those they care for. By offering the support in these locations the carers were able to take advantage of the service without needing to find additional time, make further trips out etc.

This was also appreciated by staff who delivered the project and by members of the hospital teams:

'I think a valuable part of the project has been supporting carers on the Elderly Care ward. . . they did not require follow up but did need immediate 1-1 emotional support. As a Carer Support Officer, I was able to freely observe the carers for signs of distress or concern and approach them directly, often taking them to the quiet room for some 1-1 time... this has been of great benefit to the carers at the time of acute distress when staff are very busy dealing with patients or admissions.'

**Christine Gleave, CSO, Carers' Resource**

This concept of our staff identifying and approaching carers was also well received as it relieved some of the pressure on busy staff and meant they did not have to start conversations they may not have time to complete.

'By far the most success seems to have come from having a face to face opportunity for a support worker to 'capture' carers during time spent on the wards.'

**Ruth Dixon, Team Leader – Discharge Team, Bradford Royal Infirmary**

From a carer's perspective it was also clear that they had very little time to follow up on leaflets handed to them and to make separate appointments to talk to someone about their own situation. However they would ALWAYS make time to attend clinics or visit the patient in hospital and this therefore provided the ideal opportunity to offer them some support and time for themselves.

## **Flexibility**

Another important factor for the project was the flexibility to work around the carer's own needs. We were able to telephone working carers in an evening. In one case we undertook an advocacy role between the carer and some clinical staff as she was unable to make contact with them during her working hours and those she needed to question were not available out of hours. We were able to take the questions the carer had to the staff and get their responses back to her at a convenient time for all.

## **Advocate**

An advocacy role also enabled CSOs, with full carer consent, to discuss concerns which carers either felt uncomfortable broaching or, as in one case a carer told us, they **'didn't want to bother the staff as they were too busy.'** Having a close, trusted working relationship with the staff in these situations meant our staff were able to communicate such issues at appropriate times in appropriate ways.

## **Timing**

Whilst we did receive some positive feedback on this aspect of the work from carers who used the service (**'Naelah dealt with everything promptly and the help was given at the right time'**) we believe this is an area which needs careful consideration for the future success of support pathways. In many cases the patient had only hours or days to live and this was not an appropriate time to be introducing a new person into an emotional and challenging situation.

Had the trust and relationship been built previously then it would have been suitable for the CSO to be involved at this final difficult stage. This concept is supported by the following comment from a carer: **'The support was offered at the right time but that was mainly because we were ignoring what was happening until the last couple of months when my mother's medical condition deteriorated.'** For most people this would have been too late and ways to improve this are suggested later.

## **'At Arm's Length'**

One of the strengths identified by both carers and staff involved in the project was the benefit for the users of having someone "independent" - removed from the direct relationships and situation but with a keen understanding to discuss things with. The ability to listen and to offer non-biased support and advocacy was essential.

The experience of the CSOs meant they were able to offer comparative experiences to the carers; for example to reassure that 'others feel the same', 'it's perfectly normal' etc. which helps carers to accept emotions, be more open and feel prepared to share.

**'The feedback from the carers has been very positive and they have found the information and support of great benefit, which has reduced their anxiety and enabled them to speak to someone outside of the personal situation,'**

**Matron, Elderly Care Ward, BRI.**

### **Attitude and Approach**

Not coming from a clinical background seemed to make the CSO appear more approachable but did not lessen the carers' belief and trust in their knowledge base.

Having the backing of other specialists to provide tailored information or follow on services was also recognised as an important aspect.

Not appearing to the carers to be part of the hospital staff seemed to make carers feel more comfortable asking for help and not worrying about the time taken.

One carer feeding back on the service told us: 'One of the ward sisters was tremendous but otherwise the information offered (by the hospital) was minimal and presented as if I was a nuisance'

Another explained: 'Definitely very helpful, 100% knowledgeable, if she didn't know she squirreled out the information. I never felt it was too much trouble for her to get information and was made to feel welcome and relaxed.'

Making the carer feel just as important as the patient in their own right is a key aspect. Another service user commented: 'Naelah (Carers Support Officer) could not have been more helpful, such a wonderful person, very warm and understanding with nothing too much trouble for her'

Having a support worker who could offer assistance in a variety of languages and who had an understanding of certain communities cultural and ethical needs did prove useful where referrals were taken from BME patients and carers. However this is certainly an area which would require further exploration as the number of people referred in to the service from BME communities was small. We believe building better relationships with the communities themselves and also the liaison officers based in the hospitals would improve this.

### **Continuity – 'A Lynch Pin for the Journey'**

During the end of life phase, an ever-changing stream of people become involved with the care provision for the patient. This can become confusing for both the patient and the carer. Having a permanent name and face to contact throughout the journey is extremely reassuring and can be used to help navigate and understand systems.

One carer reported: 'There was no help offered by the hospital. I felt the strong need to have someone on my side against the hospital as they kept moving my mother around and it was very confusing.'

Whilst we would never wish to see our service as being (in the carer's words) 'against the hospital' and we simply could not function without the support of the hospital and the staff, this feedback makes it clear that having a 'lynch pin' or mainstay throughout the journey is valuable – someone who is removed

from the direct treatment element but can thoroughly understand the people and processes involved and help to explain them.

The concept of continuity is reinforced from another carer who benefitted from the service and told us: 'I have had several bad experiences with hospitals, (one hospital was named here)... I still feel the hospital offers very little support or information to carers. There is little continuity of care so it is difficult to find out what is happening and what is changing over time.'

### ***HOW DID THE PROJECT BENEFIT THE STAFF INVOLVED?***

Explicitly from a staff perspective we have been given feedback on a number of benefits from having the carer support service in place:

#### **Partnership building and a '2 way street.'**

Despite the pilot's running for a relatively short length of the time, the opportunity to build partnerships within the teams where we were operating has left a strong legacy behind and the impact and increase in usage of our other services can still be felt.

One of the palliative care consultants (who we would probably never have been able to directly approach to publicise / explain our service without this project opportunity) told us; 'It is good to understand more about the role of the Carers' Resource, to have met some individuals involved and to have a clearer idea of what you do.'

#### **Immediacy / ease of making referrals**

Clinicians are busy (as are carers) – we know this. One of the main benefits of having a CSO embedded within the teams, on the wards, in the clinics etc. is the ease and immediacy for the staff to make a referral to them once a carer is identified. This was done at the MDT meetings and also at the clinics. 'We had a CSO at the last two MND clinics and this has been very helpful indeed from my perspective. Carers of MND are well known to have huge problems and it is much easier for them to ask for help if they actually meet someone at the clinic than to be given yet another task to do to phone someone up.'

**Consultant, Motor Neurone Disease Clinic, AGH.**

#### **Time saving**

Clinicians in the past have talked to us about identifying carers as feeling a bit like 'opening a can of worms'. They recognise the need to do so and many acknowledge the importance but they also worry about the time constraints and potentially lack of specialist knowledge in areas such as benefits, to deal with any 'fall out'. Knowing that a referral can be made immediately and/or the carer can be picked up there and then eased this pressure.

'The nursing staff have felt that this resource has enabled carers' needs to be recognised and managed. This is often an area that is neglected on busy acute care wards.'

**Matron, Elderly Care, BRI.**

### **Part of the Team - professionalism demonstrated, trust built**

Coming from the voluntary sector into such intense areas of expertise and professionalism could have been a daunting challenge. However Carers' Resource are extremely proud of our staff, who are equally professional and specialist in their own right, and this opportunity gave them a chance to demonstrate this and be recognised and respected as part of the team.

It is vital that other health and social care professionals understand we are all working towards the same goal and, by covering all angles and respecting one another's professional judgement, we can save time and money in the long run whilst ensuring the patient and whole family have the best possible experience.

One example from the project which illustrates this clearly occurred where the patient was pushing to go home quickly but the primary carer did not feel fully prepared for this nor able to raise her reluctance. Our CSO was able to communicate the issues to the ward staff who delayed the discharge of the patient giving the carer a little more time to come to terms with, and prepare for, the home coming. Our CSO worked intensively with the carer to help her understand and manage the stress and anxiety levels she was experiencing and when the patient did return home it was to a more sustainable situation.

Initially this may have seemed like a challenging response from the carer team, against the patient's interests and requiring more initial resource from the hospital. In the longer term it is likely to have saved money by avoiding re-admission (which would have been inevitable if the carer had been unable to cope) and by avoiding carer breakdown which would possibly have also required intervention/treatment at a cost.

The acceptance of the recommendations made by the CSO shows what a valued and trusted member of the team she had become in a short period of time and how her intervention was able to improve the discharge experience for all involved.

### **Feedback Available**

Because of the careful and extensive monitoring of the cases that we undertake we are able to offer feedback to the referring professional on the help we have been able to give and the situation itself. This is often useful for the health care staff to have a better understanding of the whole picture away from the clinical setting, reassuring the referrer that the case has been picked up and managed appropriately as well as demonstrating the professional nature of our work and.

Reliable, comprehensive systems for data collection, analysis and feedback are essential for monitoring and evaluating the value and performance of a service.

## **Going Forward in General**

Overall the project proved a huge success in building relationships within clinical and community settings and we believe these benefits will continue long term.

Our staff members made the following comments:

'It has been a real privilege to work with Rosemary Lennard and her team (palliative care at BRI) they have been informative and supportive, they have made referrals, and telephoned referrals in too'

'Dawn Parkes (Matron, Elderly Care) has been incredibly supportive of the project; the team often have been very busy but are happy for me to go around the wards to talk to carers directly, taking referrals and providing emotional support as needed'

It is also pleasing to see in the feedback from staff involved at the hospital that our involvement has made them re-evaluate some of their existing processes which again should offer long term improvements for carers.

'It has become much clearer that we have gaps in our processes and need to use trigger points in our assessments here in order to firstly raise awareness, and secondly to signpost people towards Carers' Resource.'

**Clinical Lead Discharge Team, BRI**

## ***BARRIERS AND AREAS FOR IMPROVEMENT***

As with every pilot project not everything went 100% smoothly or perfectly and several barriers were encountered. Many of these were overcome within the timescale and others have given us scope to develop the project before future roll out.

### **'Too late, too little'**

The most critical issue to be overcome is the timeliness of making referrals into the service. Many of the referrals came at a very advanced stage of the journey. Sometimes this meant that the carer did not wish to take up the service (although this happened in relatively few cases). On other occasions the cared-for died either before we had chance to get in touch or very soon afterwards which meant we were unable really to do much useful work with the carer.

To offer the best possible service to carers best outcomes are achieved if we meet them early in their journey, even if their needs are unclear or very low to begin with. The trust built will mean a much more comfortable progression into more intensive use of the service at later stages or points of crisis.

There are various ways to improve this including the allocation/positioning of staff members, training and raising awareness and understanding of the service – as well as by tackling some of the other barriers detailed below.

## **Right person, right place**

Identifying the correct teams and locations to link with our staff was difficult from a standing start on a very short timescale. With hindsight we chose some locations which were not ideal and we overlooked others where we should have been.

- Discharge Team – this was relatively unsuccessful in terms of referrals: they seemed simply too busy and had too many other issues to deal with very quickly in the case of end of life patients who need immediate discharge. We do believe there is a valuable link to be made here on a more generic basis. We intend to continue to build links with the team, who were very supportive, and to work on such aspects as avoidance of re-admission.
- Hospital palliative care teams – this was a huge learning opportunity for the staff and they valued the chance to work within these teams. We received some referrals. The majority of patients receiving treatment from these teams, however, are at an advanced stage (level 2 or 3) and this contributed to the difficulty of late referral and little input. Additionally there may also be other specialist support available to many patients/carers at this stage from psychologists.
- Elderly Care Wards – this was probably the most successful link we made during the project. The CSOs not only worked with staff but were free to directly approach carers during visiting times and the immediacy and flexibility offered by this was well received. The only difficulty encountered here was the lack of continuity of staff (discussed later)
- MND clinic – once again this was a hugely successful element of the project. We were able to speak to all carers bringing patients to the clinic both on the day and for regular follow-up interventions where required. For progressive degenerative conditions such as this it is extremely valuable to forge links and build relationships with the carers at the earliest possible stage so they can be supported throughout the journey. We would like to look at creating links with further specialist clinics in this way but it is proving quite difficult to identify them and make an approach.
- Community and Hospice teams – this is an area where we were sadly not linked in. For future projects we recognise that these teams are the ones most likely to be dealing with the level one patients and therefore providing us with access to carers at an earlier stage. However we did find resistance from many of these teams and barriers such as perceived competition and condition lotteries. See below.
- BME Community work – this was sadly an area where we were well prepared and well placed to deliver but the referrals into the scheme from the hospital liaison worker were not forthcoming. There needs to be more work done to build better relationships and a clearer understanding of how the roles could complement and work together rather than being seen as duplication.

## **Training and information sharing**

Due to the very limited timescale of this project we had to approach the team leads, explain the project, offer briefing papers and one to one discussions but we then had to rely on them to cascade this down to their teams.

In many cases this did not seem to happen, whether due to time constraints, lack of opportunity or more training needs. This led to lots of confusion on the wards and among some teams whereby a different person was on duty/in charge each time our CSO visited and they did not know of the project or understand the system for referrals etc.

This was frustrating for our staff who felt they had to keep justifying their presence and almost 'begging' for support from the clinical staff. We believe that given more time for a sustained project this could be overcome through training, briefings to all staff through existing channels and continued presence by our staff.

## **Signposting vs Referral**

Many health and social care professionals undertake their responsibility to carers by telling them that they should look after themselves and that information about support for them exists. Some health and social care professionals go further and suggest carers should contact Carers' Resource, some even encourage it.

However we have found where *signposting* rather than *direct referral* is the chosen option relatively few carers follow it up straight away - if ever. At end of life stage even fewer carers do so as they have so much more to cope with, physically and emotionally.

There is evidence to show carers pay little attention to their own health and wellbeing and this also reflects that they are unlikely to seek help for themselves unless encouraged.

Our learning and our plea following this project is that '**Direct Referral**' into a service by a professional is by far the best way to ensure carers will accept the 'label' carer – they respond because someone in 'authority' has directed them to have help and support in their own right.

Carers Centres and specialist support services are keen to work with other professionals to make this referral as simple as possible including offering referral pads, linked workers, telephone and fax opportunities and online referrals systems. However the ultimate goal would be to develop some shared systems whereby an automatic, perhaps electronic, referral could be made once a carer is officially 'identified'.

## **Gatekeeping**

Our project encountered professionals who for different reasons undertook 'gatekeeping'. Some did so because they did not fully understand what was on offer, others because they thought the case 'too complex' for us to

manage or even 'too low level' to merit support. Another group simply stuck to tradition, refusing to acknowledge a new service and preferring to refer only to those they had previously used which meant a disjointed approach, condition lottery (see below) and carers missing out.

This contradicts 'choice and control', with carers empowered to choose whether or not they wish to take up the service. It also means they are not being offered the full range of support available to them. If a service were to be established in the future it would be advantageous to implement protocols or referral pathways *to ensure it is not the choice of the professional whether or not to offer a service but actually the choice of the carer whether to accept it.*

### **Competition elements – both real and perceived.**

'*We do that already*' was a popular response when initially discussing the project with palliative care specialist teams both in hospitals and in the community. There was clearly a fear from some of the health professionals involved and some of the condition specific voluntary sector agencies that this project was duplicating work, adding to the confusion and complexity of accessing services and potentially endangering existing projects. This was quite simply not the case.

The key aspect to remember that ours is a service **FOR CARERS** and that carers do not have the condition or illness in question. Whilst condition specific organisations have many strengths, *their* focus starts from the patient. Of course it is important to have empathy for the condition of the cared-for. Uniquely, however, our service starts from the carer, recognising they need support in their own right – support to fulfil their own hopes, dreams and aspirations and to cope with their own very personal fears and challenges as well as support with caring. The carer is the expert partner in care. They need specialist help.

Once again we see this being linked to gatekeeping: health and social care professionals should not decide that once a carer was in touch with one particular organisation they did not need to know about others – thus limiting their choice and control and access to all the support available.

It is clear that whatever service is being offered that it needs to be a simple, straightforward and bureaucracy free referral system and that carers do not get subsumed in tensions behind the scenes of agencies fighting for survival or higher numbers through their doors.

### **Condition Lottery**

We would suggest that a condition lottery is not dissimilar from a postcode lottery and must be avoided. A person's condition should not dictate if – or what - support their carer is offered.

Some conditions have many more support networks, national and local charities and activities associated with them and available to them than

others. Where a carer can only access support through a condition specific source, they often feel their future is being laid out in front of them in ways they're not ready for. Attending a support group and meeting people with experience of advanced conditions (people who've had time to adjust to their predicament) can be really upsetting.

By offering an holistic service for carers as a starting point, we are able to ensure that carers are provided with support tailor-made to *their* needs, with appropriate onwards referral.

Additionally, as a generic service and a gateway for all carers, we can give a much broader brush approach and wider peer support opportunities. We are able to identify unmet need and gaps in provision and respond to them locally and sensitively, with the carers needs centre-stage.

### **Permission to proceed**

Finally came the issue of conforming to the necessary protocols and procedures in a very short timescale project. This involved needing honorary contracts, information sharing protocols, etc. None of these proved insurmountable, thanks to the willingness of the hospitals and teams involved to work in partnership; however they can cause delays and do need to be factored in for future projects.

## **AREAS TO DEVELOP / GAPS IDENTIFIED**

So what have we learned from providing specialist support for carers of those nearing the end of life both in hospital and at home? Where are the areas for potential future development?

*It is very clear that there is a need for such a scheme and it is very well received by both clients and professionals alike.*

**Earlier identification and referral of carers is needed** – the last few days / hours of the patient's life is too late to introduce carer support and the workers are unable to make a real difference. We need to ensure that carers are spotted earlier and referred for support onto the scheme before crises are reached and time is running out.

Carers and professionals need to understand the service is available to them from the moment of diagnosis so they can build a relationship and access it as suits their needs. Work here needs to identify possible trigger points for different stages of health care to enable identification as early as possible including linking with GP palliative care registers etc.

**Emotional support is vital** - This project has proved that personalised support for the carer is the most highly sought after and valued aspect of the work we undertook. It can very easily be misrepresented as 'tea and sympathy' but this is not the case. ['Someone who asks about me'](#), ['someone](#)

removed from the situation', 'someone to ask the difficult questions to', 'someone who is on 'our side' were all statements made by carers using the service.

There is a real need for the opportunity to talk openly, without guilt, with less time restrictions than in clinical settings to a specialist 'listener' who will travel the pathway with the carer.

**Distance support** – One of the areas we identified as a need for further, specialist support was where a caring relationship was taking place 'at a distance' This included members of the armed services, students away at university or prisoners. In these cases the carers are still struggling to come to terms with the situation and in need of help and support but this can be very difficult in terms of communication and access to help. The help they require is different – less practical and more emotional and information sharing to feel they are still a part of the family.

This needs further consideration and exploration for potential joint working with services that do exist or development of new ones if there is no provision.

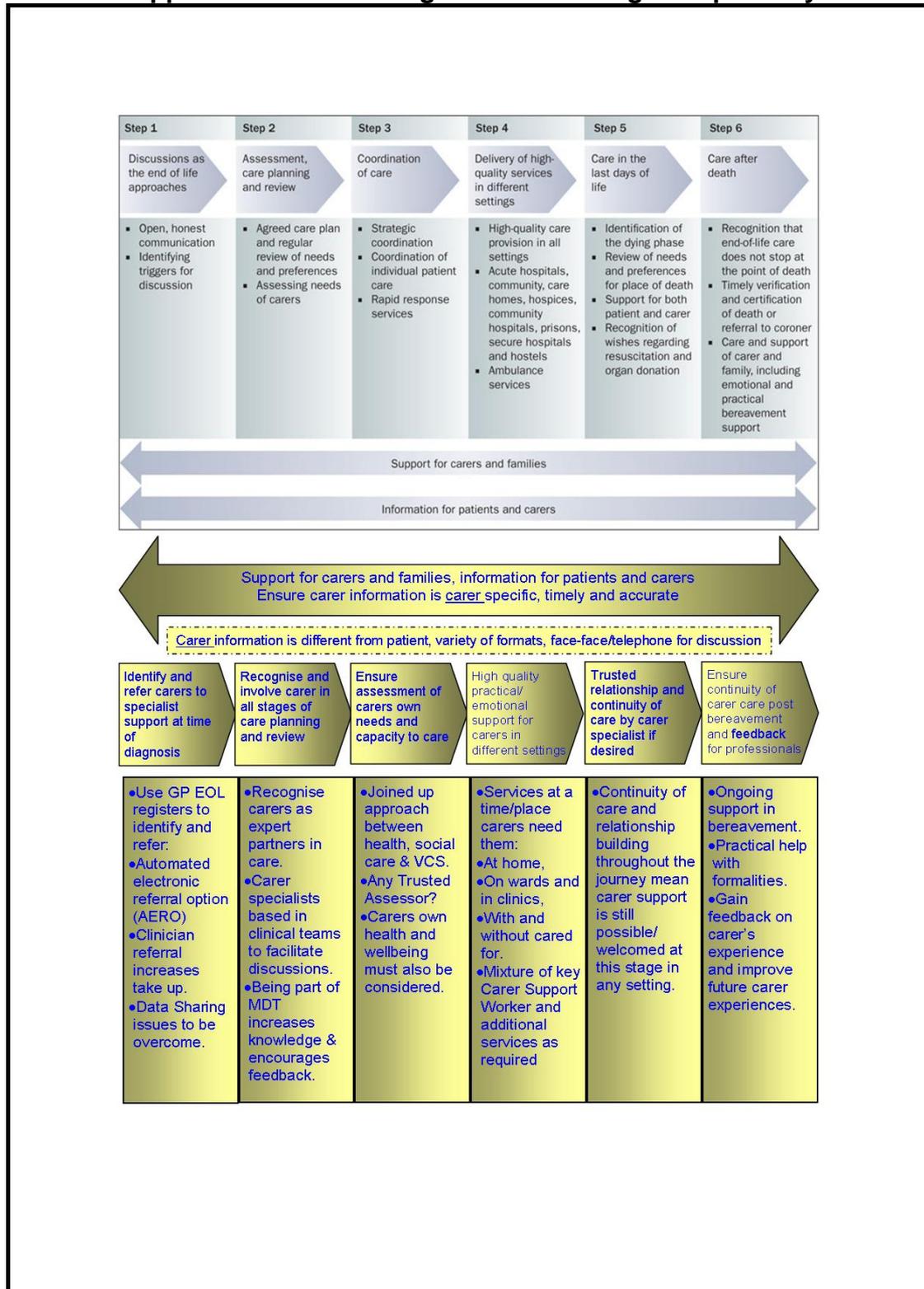
**Impact of employment**– many of the carers were working full or part-time. They were having real difficulty both accessing information / support from clinical staff out of hours *and also* experiencing lack of understanding of the situation and support from employers. The need for an advocate (who can operate alongside the carer in these situations) asking questions, relaying information or explaining difficulties to other professionals and employers can be crucial in helping carers maintain their employment or better understand and support their loved one. There may also be a role for working with employers to better understand the situation and how to provide better working practices, policies and carer awareness.

**No statutory input** - there was difficulty for carers accessing support (including bereavement support) in cases where the patient was refusing to accept help / input from any statutory services. This meant carers were often not identified, or referred for support in their own right to statutory services.

This also happened if the level of need was deemed 'too low' for statutory eligibility criteria.

# RECOMMENDATIONS

## The Proposed Carer Support Pathway mapped to function alongside the existing EOL pathway



EOL Pathway diagram reproduced from Department of Health (2008) *End of Life Care Strategy—promoting high quality care for all adults at the end of life* © Crown copyright.

The existing end of life pathway recommends that carer and family support and information is a cross cutting theme but gives little guidance. As a result of this project, we have devised a Carer Support Pathway to suggest how this could be accomplished alongside the patient pathway, what form support could take and how to achieve integrated care for carers and patients.

It is important to acknowledge that Carer Information is very different from Patient Information. It should start from the carer and examine / explain how progression of a condition, medications etc. will impact upon the life of the caring family. This is critical to every stage throughout the pathway and should always at least be produced with support from, or in partnership with, a carer specialist agency. Whenever necessary/possible it should be disseminated to the carer by a specialist who can discuss and clarify any aspects.

The key stages in the pathway for carers are:

**Early identification and referral** by health / social care professional to increase likely take up of support. As patients are entered onto the EOL register, the carer details are also recorded but little if anything is done with them. We believe an automated electronic referral should be possible direct to a carer support agency (with a choice to 'opt out' rather than the requirement not only to 'opt in') which will ensure sensitive first contact is made.

Anyone making the diagnosis / breaking the news to a patient that they are entering the last year of their life should be responsible for ensuring at least the primary carer is identified, acknowledged and referred for support irrespective of who or where this is happening i.e. GP practice, in hospital, in the community.

**Inclusion in Care Planning and Assessment:** - Recognition of carers as expert partners in care by the professionals involved is key. The National Carers Strategy clearly holds this to be a main principle and we believe the same is true in this pathway.

Carers will be vital to sustaining care throughout the EOL journey and are therefore pivotal in deciding what and how this needs to happen. Carer Support Officers who have picked up the referral should be available to help facilitate important discussions around care planning, discharge etc – and their own lives and commitments. They can ensure the carer fully understands the process and is able to clearly and honestly express their views, concerns and level of capacity to provide care.

**Carer Assessment** – better systems and avoidance of assessment fatigue and repetition. It has become clear to us throughout this project that a carer will be faced by many different assessors and assessments. There is a need for services to appropriately share data and work together. This includes health, social care and any voluntary and community sector organisations

who are involved in the provision of care to ensure integrated care and best possible service and outcomes.

Current protocols and systems make it difficult or impossible for cross service boundary sharing of information which means telling the same story many times to many different people. A system of one trusted assessor to support the carer through the assessment process and data sharing protocols would reduce duplication and harassment for the whole family.

**Appropriateness of service** – timing, location and format (including cultural/language knowledge). Just as the major focus has been on where the patient wishes to be treated and ultimately to die, so too do we need to see a focus be on when, where and how the carer wishes to receive support and meet these needs in an appropriate manner which fits with their life outside caring also.

Respect for carers as individuals, not as an add-on to a patients, is vital. So too is understanding that carers' need for information and support may well be different from (and sometimes even at odds with) the patient. Carers' needs should be met by professionals and carer specialists as a matter of importance - this will ensure more successful, sustainable care packages.

The existence of a carer specialist service makes it easier to deal with conflicts of interest. In cases where carers wishes differ substantially from those of the patient a well embedded, trusted carer support worker can prove invaluable in facilitating discussions and helping to reach suitable compromises which leave everyone feeling more comfortable and secure.

Where specialist community liaison roles exist, there should be closer joint working as the carer still needs and deserves specialist carer support in their own right alongside the liaison work which is being offered.

Having support workers embedded in clinical and community settings also offers an immediacy, removes more barriers to access and improves feedback and communication among all parties.

**Continuity of care and relationship building.** Caring does not stop at any point on the journey and often intensifies as the situation progresses. Early identification and referral into a key carer support worker who will then remain with the family for the duration of the journey is the mainstay of this pathway. By building trust and understanding of the situation during the early period, the support worker can remain a constant and be much better able to be involved as things deteriorate and carer need levels increase. They are accepted by the family even during the last days of life and feel more comfortable in their own role as they have substantial background knowledge of the family.

**Post- bereavement needs change but remain**

After the patient has died, the carer often needs continued support with both practical and emotional aspects of moving on. This encompasses aspects

such as funeral plans, changes to financial and legal documents / benefits and an experienced listener. Joint support from specialist bereavement services may also be required and can be better introduced or provided by the trusted support worker.

Additionally feedback on the experience from the carers' perspective for the professionals involved can be gained by the support worker without it feeling like an intrusion and should result in a more comprehensive, honest and constructive feedback system.

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All quotes in [blue](#) are taken from written and verbal feedback (transcribed telephone interviews) with professionals and carers involved with the project.

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