

HOSPICE NEIGHBOURS

A Case Study and Toolkit



*everybody
needs good
neighbours*

St Nicholas
Hospice Care

A Registered Charity No. 287773

Dear Colleague

Thank you for your interest in St Nicholas Hospice Care and our Hospice Neighbours Scheme.

I have worked in hospice care for nearly thirty years and I know one thing that can make a real difference to families is the compassionate support that one human being can give to another.

We launched our Hospice Neighbours Scheme in 2010 with the aim of building teams of local volunteers to provide practical support and companionship to those living with life shortening illness, in their communities based in West Suffolk and South Norfolk. Today we have 20 teams of volunteer hospice neighbours operating from eight hubs across our region. They are providing valued services to patients referred via the hospice itself and also through our community partners. The service is continuing to grow and develop as our vision for the future of hospice services evolves.

The production of this case study and toolkit has given us an opportunity to reflect on our journey since launch and the lessons we have learned along the way. It is designed to answer the basic questions 'Why we set this scheme up, what we did and how we did it'. We hope that you find it interesting and thought provoking and that it inspires you to think about how a volunteer scheme similar to this could work in your part of the world.

If you have any questions about the scheme which are not addressed in the guide then please do get in contact.



Barbara Gale

Chief Executive

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Chapter One. Why Hospice Neighbours?

Creating Compassionate Communities

Through Hospice Neighbours we aim to find one way of mobilising and equipping teams of local volunteers to support those in their community who face end of life challenges. We aim to support patient and families to continue normal life for as long as possible.



1.1 Shaping the vision

The story of how Hospice Neighbours came into being, is one that begins and ends with patients, carers and family members. As we have spent time listening to users of our services, we have heard an overwhelming desire repeated time and again, for the patient to remain at home for as long as possible and to spend their last days in familiar surroundings in the presence of loved ones.

Back in early 2010, Chief Executive Barbara Gale was particularly affected by some feedback she received. Whilst hospice services were all highly valued, what was missing was practical support and companionship at home, to help patients and their families maintain life as normal for as long as possible. This gap opened up the potential for a volunteer led service to be developed in the local community, supported and equipped by the skilled professional staff of the hospice. That is where our story begins.

1.2 The case for change

We are all aware that in the UK our society is ageing. The statistics are well documented and the predicted consequences of our ageing population are increasing levels of unmet need for palliative and end of life care. Recent research tells us that many people wish to die and be cared for in their own homes but due to the increased demand on our care systems as things stand *'most people will not die how or where they would wish. (Dying for change, Demos 2010).*

There are also likely to be increased numbers dying over longer periods and requiring higher levels of support for longer. Research carried out by the Cicely Saunders Institute stated that by 2035 it is predicted that half of all deaths in the UK will relate to people aged over 85, many of whom will suffer from complex conditions and increasing frailty. In these circumstances, many will have lost a partner and have few or no family carers and relatives living nearby. Financial constraints in the wider health and social care systems mean that resources to help people 'die a good death' are increasingly stretched. Source : Future Ambitions for Hospice Care : Our mission and our opportunity. Oct 2013. Help the Hospices Commission)

'How we care for the most vulnerable at the most vulnerable of times is a measure of our compassion as a society'

Dame Claire Tickell, Chair, Commission into the future of Hospice Care

pioneer new approaches to emerging challenges. The challenge for us has been to develop a volunteer based scheme as one approach to meeting the needs of our local community both now and in the future.



1.3 Local need

Our area covers West Suffolk and South Norfolk with a population of over 260,000. The area is predominantly rural with the medieval market town of Bury St Edmunds at its centre. Other key centres of population include Newmarket, a home of international horse racing and the smaller market towns of Haverhill, Thetford and Sudbury. The area is well known for its rich agricultural heritage, rolling countryside and historic tourist attractions. This combination of a few market towns and numerous small villages dispersed around the countryside, served by minor roads and country lanes, presents all the care services with geographical challenges.

In our service area, people aged 65 plus currently represent nearly a fifth of the local population, but this will increase significantly so that nearly 40% of the population will be aged over 70 by the end of the next decade. Of this older age group, approximately one third currently live in rural areas where the provision of care services is more challenging and transport more difficult.

(Source NHS Suffolk report 2011 West Suffolk Clinical Commissioning team annual report 2013/14)

1.4 Learning from others



The idea for Hospice Neighbours came from our Chief Executive Barbara Gale. Barbara heard from her aunt in Germany about a local GP who trained volunteers to sit with those who were dying. She began to research other examples and found a number of successful models of volunteer led support schemes around the world which were providing valuable

support in challenging settings to those facing the end of life.



One of the largest schemes worldwide is the ***Neighbourhood Network for Palliative Care*** set up in the state of Kerala, India. The scheme run by Dr Suresh Kumar trains thousands of volunteers to create a vast social support network in Kerala covering nearly 12 million people, supporting palliative care professionals by easing the pain and burden of end of life care.

(Source : Models of Developing Palliative and End of Life Care in India. Dr Suresh Kumar. Current Opinion Support Palliative Care Vol 7 no 2 June 2013)

In the UK, the ***Compassionate Communities Scheme (Co Co)*** which is run by the local community in Shrewsbury and supported by Severn Hospice has developed a volunteer befriending service to help people with long term illness stay in touch with their community.

In the rural communities of ***North West Ontario, Canada*** there is a scheme which trains teams of hospice volunteers to provide friendship and support in rural communities where the majority who face end of life challenges are physically frail, 'slow dying' seniors. The ultimate aim of that scheme is to ensure that '*no one dies alone*' in their community.

(Source : 'So no one dies alone: a study of Hospice Volunteering with Rural Seniors' Journal of Palliative Care Autumn 2007)

Our Hospice Neighbours Scheme was one of the first of this type to be set up in the UK and builds on some of the learning from these projects. Our long-term aim is to see ownership of the scheme devolve to the community itself: this is why it has been set up with a far lighter touch than our clinical or traditional volunteer services.

Chapter Two . What is the Hospice Neighbours Scheme?



Hospice Neighbours aims to provide practical support and companionship in the home to people and their families living with life limiting and long term conditions in our area.

When people are facing death their world does not stop and all the little but important household tasks still need doing. Practical tasks offered can include taking the dog for a

walk, light shopping and gardening, or sitting with a patient whilst their carer goes out.

Companionship for the patient or their carer is the most requested aspect of our service. It enables patients or their carers to continue to connect with their local community and at a time when they may otherwise be isolated and lonely.

Other professional groups and charities that provide services in our area to those with life limiting and long term conditions do not typically have the time or resources to address practical and companionship needs. By supporting people in this way we aim to enable many to live fulfilled and meaningful lives for a good period of time and to remain at home.

2.1 How does the scheme work?

The Hospice Neighbours service is essentially a matching service. It aims to match the need of our service users for companionship and practical support with the availability and skills of our teams of local and trained volunteers.

The service is driven by the needs of the patient or carer.

Matching neighbours and patients so that they can find things in common and have similar interests and backgrounds is a really important part of the service. It helps develop a sense of understanding and friendship which both parties involved can benefit from. Our volunteers often tell us that they find their visits incredibly rewarding and receive as much back from the person they visit as they give. One neighbour described how her patient had shown her how to use social media which she found very helpful.

Companionship has emerged as the service which is most requested and valued by patients and family carers and regular visits of one to two hours are the norm. However, there are no definitive guidelines imposed and ultimately the length and frequency of visits and the activities that take place during the visit are determined by what works for both the patient and the neighbour.

Since 2010, the scheme has provided over 12000 hours of support to patients living in West Suffolk and South Norfolk, the majority for companionship.



Referrals are received from other teams within the Hospice, other service providers in the community including the NHS, Social Care and charitable organisations, as well as through GP surgeries. Some patients are referred by friends or family or they can self refer.

In some cases we will be given very detailed information about a patient and their needs which means that we can get a clear picture of which neighbour to match them with. In other cases we have little information and a telephone call is made to collect basic details and assess the needs and requirements of the individual.

The service operates through teams of volunteer neighbours and their team coordinators who are currently supported by two employees of the Hospice.

2.2 Who are our volunteers?

Hospice neighbour volunteers are people from many different walks in life who have spare time and a desire to offer something positive back into their community. A large number of volunteers are retired, and this includes some professionals from other care services who want to get back to working directly with people.

We also have busy mums on our books and people who work both full and part-time. The majority of volunteers tend to be female. Although we do have a good number of male volunteers, there is always a need for more as a good gender balance is helpful in terms of the matching process and our ability to provide a variety of support.

All our volunteers neighbours are **interviewed** before being accepted on to the scheme to ensure that they are fully aware of what will be involved and have the maturity to deal with the emotional demands of working with people living with life shortening illnesses. They are also subject to a range of checks and references to ensure their suitability for the role.

Volunteer team coordinators, who manage teams of neighbours in their locality are often recruited and trained from the pool of neighbours in a particular area. Coordinators tend to be individuals who enjoy using their experience to offer advice and support and who have the time and availability to react quickly to matching a referral or communicating critical information in a sensitive way e.g. if the patient dies.

Do we ever turn volunteer applicants down?

We do stipulate that volunteers must be over 18. If we identify that a volunteer applicant is vulnerable in any way e.g. as a result of a recent bereavement, then we would normally suggest that they defer joining the scheme to avoid exposing them or their patient to potential harm.

2.3 What basic training are volunteers given?

All volunteer neighbours attend **induction** training which is run in two back to back day-long sessions. All neighbours must complete their training before they are allowed to meet with a

patient to ensure that they understand the hospice ethos, have an orientation to palliative care and are equipped with a basic level of knowledge in areas such as health and safety and risk assessment.

Following a volunteer's induction, their local coordinator will set up a match with a suitable patient and support them as they prepare for their first visit. Follow up conversations are held over the phone or face to face after the visit so that any concerns can be discussed and the neighbour has a chance to confirm that they are happy to continue visiting.

Ongoing training and support is offered to all neighbours, some of which is mandatory. This is described in Chapter Three.

2.4 How does the hospice actively support and manage the scheme?

There are two members of the hospice staff (1.6FTE) currently involved in supporting the scheme, a coordinator and an assistant. They provide the following services which require professional training and access to highly confidential information :

- < Provide a central phone line for all referrals
- < Record all referrals and matches and track progress
- < Notify volunteers of any changes e.g. patient dying
- < Recruit and handle vetting and checking processes for volunteers
- < Run induction and skills development courses
- < Organise local volunteer support groups
- < Support volunteer coordinators
- < Keep records of activity for feedback to stakeholders
- < Develop networks to promote the service in the community

2.5 How are referrals made?

Referrals come into a central point usually by phone. At this point, basic details are noted which include name, address, contact numbers, carer/family details, service requirements and brief details about the patient e.g. medical history, mobility and toileting arrangements.

Details of the referral are then passed to the volunteer coordinator for the locality in which the patient lives. The coordinator then arranges a match with the most appropriate volunteer in their team based on locality, skills and overall fit.

All coordinators and neighbours are given briefings on confidentiality and handling sensitive information and are asked to sign a confidentiality statement before they take on an assignment.

Do all referrals get accepted?

We accept any referral where the individual has a life limiting or long term illness and the individual lives in the area we serve. Priority is given to palliative patients and the most urgent/needy cases if resources are stretched. People with dementia are also accepted for the service when there is an available hospice neighbour.

2.6 Confidentiality and risk

2.6.1 How do we maintain patient confidentiality?

Only minimal medical information is passed on to volunteers and it is largely down to the service user to tell their neighbour what they wish them to know. All neighbours are given training on handling sensitive personal information and are bound by the same rules of confidentiality as all other hospice staff and volunteers.

2.6.2 Are services users assessed before being matched to minimise risk to both them and volunteer neighbours?

Where referrals are made from outside the hospice, there may be no assessment beyond the information supplied by the referring person. Coordinators may choose to assess referrals first, depending on the information received. In some cases an assessment may be done by a neighbour who will have been trained to assess risk and report any concerns back to their coordinator. Neighbours are aware of how to request help or back up services if the need arises and as a lone worker are always asked to let someone know the time they are visiting and when their visit ends.

Chapter Three. How did we get the scheme up and running?

3.1 Engaging partners in the community



In 2010, the West Suffolk PCT identified clear pressures on end of life services in the community and that pressures were likely to increase in the years ahead. Through negotiation with our Chief Executive and discussion about the proposed scheme, the potential hospice neighbour contribution to meeting the challenges was agreed and start-up funding offered.

Discussions took place with a range of community partners including District Nurses in the two areas of West Suffolk and South Norfolk, local Social Services managers and care agencies. This developed our understanding of unmet need and helped greatly in shaping the way the service was designed so that it reflected what statutory agencies and professional staff didn't have time to deliver.

There were other volunteer groups working in some areas but we established that none had specific, specialised experience in supporting people with a terminal illness and none were

supported or trained by professional staff who were experts in this field. The most pressing needs we found were for practical support and human contact/companionship both for carers and patients.

Through consultation and discussion with all relevant agencies and volunteer groups we sought to ensure that we could design our service to complement other providers, seeking to avoid any unnecessary overlaps and filling some of the gaps that other services did not cover.

The importance of working in partnership in the community to deliver end of life services has continued to be a theme throughout the evolution of the scheme.

3.2 Securing a budget and resources

Once the initial concept for the Hospice Neighbours scheme had been established we needed to prepare a cost estimate for its delivery before appropriate funding could be sought. We decided to set out our budget over a three year period as it was clear that there would be need to be a higher level of investment of people and finance in years one and two to set up the scheme. After that the resource requirements would diminish significantly.

Valuable start up funding was provided through the local Primary Care Trust and once we had established a presence in the community and could provide evidence, both qualitative and quantitative, relating to the value of the service delivered through our volunteers, we were successful in attracting further funding from a local trust fund and the Big Lottery. As a high impact project, with relatively low running costs and high community visibility, it did lend itself to attracting funding from trusts and foundations.

A key learning point was the need to collate evidence and service data right from outset to demonstrate the value of the service to potential funders.

We used case studies, interviews with patients and neighbours as well as hard data on hours of care and type of support provided. We have also found it useful to invite both patients and neighbours to meet fundraisers on occasions.

3.3 Project planning



In our case we decided to go for a phased roll out across our area with two different areas of West Suffolk chosen for an initial pilot. We developed a high level project plan which covered three main phases of the scheme launch and roll out as outlined below:-

Phase one – Recruitment and Networking in the Community (Three months)

Key milestones :

1. The Volunteer Service Manager for the hospice was seconded to the Hospice Neighbours scheme to manage the project, along with a deputy, and other support staff including a trainer.
2. The first tranche of volunteer neighbours and coordinators were recruited in the two pilot areas of West Suffolk.
3. Networking meetings were held with interest groups in the community including district nurses, social care teams, GP surgeries and carer organisations seeking to raise awareness of the service and ensure a flow of nominees.

Phase Two – Scheme piloted in two geographical areas (Six months)

Milestones :

1. Launch of the scheme in two contrasting parts of the area – Haverhill a town in the south of the county with a good community spirit and Stanton a village in a rural area.
2. Evaluation of the two schemes and the lessons learned to help with the roll out of the scheme across the whole region.

Phase Three (ongoing)

Further expansion of the scheme in areas across the county building on lessons learned from the pilot phase. A rolling recruitment campaign continues across the region, ensuring that teams are well supported with trained volunteer neighbours and that coordinators are responsible for a maximum of ten neighbours each.

3.4 Publicity and initial recruitment



We designed a marketing plan to meet the objectives of our scheme launch:

- To raise awareness and understanding in the community amongst patients/agencies
- Recruit volunteers
- Foster relationships with existing agencies and organisations

We used a range of media channels, including our own news magazine and website, information leaflets, posters in libraries and GP's, press statements and articles, local radio interviews, volunteer magazines and community newsletters. We also designed a 'house image' (see above) to be used for all publicity which reflected our aim of enabling people with life shortening illnesses to stay at home with support for as long as possible.

Hospice neighbours advertising image:



3.5 Planning induction

As we set about the process of recruiting our first set of volunteers we also began the process of deciding what processes and procedures should be in place for the scheme to operate in a fair and safe way and what should be included in the initial induction training.

A hospice trainer came on board to help us develop a hospice neighbour handbook and an induction course which was mandatory for all prospective neighbours.

3.6 Further support and development



We developed a three-fold approach to the training and development of our neighbours following induction and initial assignments:- .

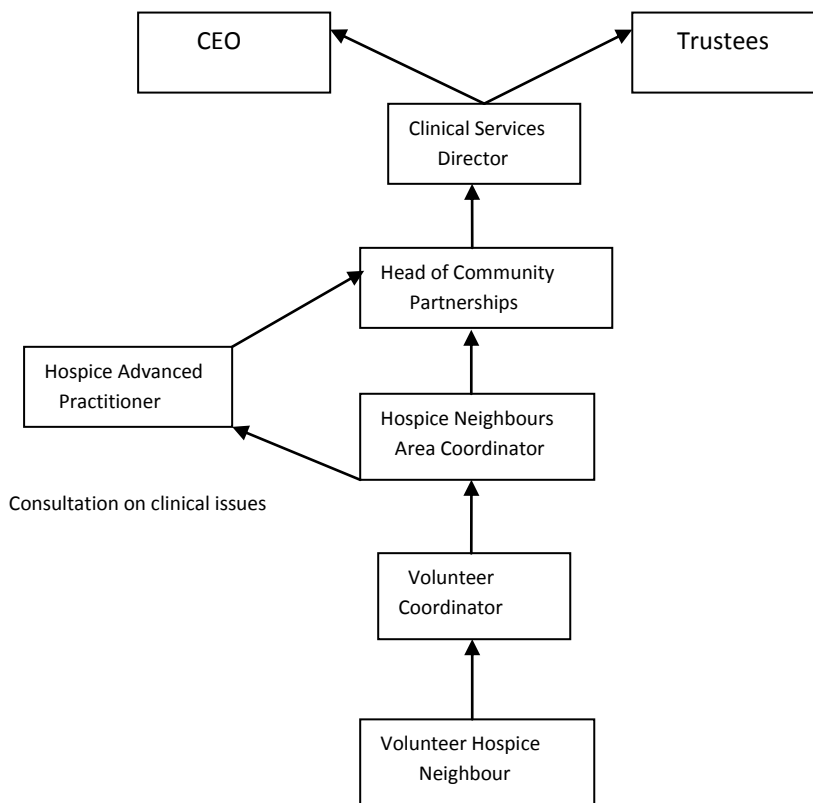
1. **Access to their volunteer coordinator** or member of staff working on the scheme during the day, by phone, for dealing with urgent queries. The ratio of neighbours to coordinators within any one team is roughly 10:1.
2. **Support groups** run by volunteer coordinators in each locality. This brings teams of neighbours together to discuss their visits in a confidential environment and share experiences and learning, sometimes with a hospice professional present for additional guidance.
3. **Development days** run county wide. These are opportunities for all hospice neighbours and coordinators to meet up for development, encouragement and to build a sense of community amongst the county wide team. Speakers from different areas attend the day to run sessions on a range of topics which help equip neighbours to offer more to their patients. Topics have covered practical skills like hand massage, to information about wider services to help with signposting.



3.7 Governance

The system of reporting which connects the scheme with the rest of the hospice and its trustees has been designed to ensure that there is ongoing quality assurance and service monitoring in place as well as clear overall leadership.

The scheme reports into the Clinical Services Director for operational matters and clinical leadership and then to the Chief Executive and Trustees – see below.



3.7.1 Quality assurance

The support group structure for local neighbours is a key means of airing and addressing any areas of service quality. Questions or issues around the service can if necessary be taken beyond the coordinators' group to the Area Coordinator, who may also refer upwards to the Head of Community Partnerships, or to the Hospice Advanced Practitioner for issues around clinical practice.

A separate reporting mechanism is in place should there ever be any incident or complaint

regarding the service. Service User Advisory groups are also consulted from time to time on matters of service delivery.

3.7.2 Service volume and activity

A quarterly report is made available to staff, managers and trustees so that service trends can be reviewed and any successes and difficulties communicated. Peaks and troughs in the service do occur and it is helpful for staff and managers to see where there are pressure points or times of lower activity for neighbours, both of which can cause issues for volunteers and their coordinators. This helps manage the pipeline of cases and the efficiency of the service.

Reports have also been produced to meet the needs of key fundraisers/stakeholders to ensure that their needs for information are met.

Chapter Four. How do we know the service works?

Evaluating the service from both a qualitative and quantitative point of view continues to be a vital part of our service development.

4.1 Qualitative Evidence

An MSc Dissertation written by Rev Charles Amoah an employee of the hospice, in 2013 has enabled us to provide a wealth of qualitative evidence to support the value of the service which is based on the actual experience and response of service users.

(Quote from one patient about her Hospice Neighbour)

' She has made me feel that I am still alive ... and that I can still take part in life'

The dissertation found that there were four key areas of the service which were particularly valued by patients.

i. Friendship

The report found that the **friendship** element of the service was hugely valuable in counteracting both the isolation and emotional distress which can arise from the challenge of living with life limiting illnesses:

'I felt so ill. By the time he was going I was really appreciative that he was there. He changed my day and made it alright again'. (Quote from patient)

ii. Practical help

The dissertation also highlighted the significance of **practical help** given to the wellbeing of patients – not only did it help relieve the burden of getting things done but in some cases it built confidence to do things themselves :

' When it's hoovered, everything's all nice... that encourages me to polishing perhaps myself the next day'. (Patient quote)

iii. Respite for carers

Providing much needed **respite** for family members was another area of the service that was highlighted. Caregivers repeated that they needed to find some 'me time' and hospice

neighbour visits have provided carers with a breather to recuperate from the demands of care:

'... it gives Micky (name changed) peace he says it is a good idea to have someone to keep an eye on me' (patient quote)

iv. Making Connections with everyday life outside

Providing a **bridge** both connecting patients with mainstream society and providing an element of normality, was also mentioned as extremely valuable to patients.

'I didn't know what was going on outside... the local paper only reports on incidents... it doesn't hold a conversation with you'

'I couldn't even walk into town but she'd come with me... we'd go for a cup of tea...so she helped me get back... into mainstream society'

4.2 Quantitative Evidence

We hold data in a detailed activity report updated by our Area Coordinator. This allows us to keep an accurate record of the overall volume and areas of activity provided through our teams of volunteers. The data is collected from each volunteer on a monthly basis by the team coordinator who sends it to the central support team for recording.

Our records show that :

During the period April 2013 to March 2014

There were 3592 hours of support delivered by neighbours across West Suffolk and South Norfolk.

Of these hours – 1820 hours (51 %) were devoted to providing companionship

- 1142 hours (32 %) were devoted to domestic support around the home

The remaining 630 hours comprised gardening, shopping, driving, complementary therapy, spiritual support and pet therapy (17 %).

During the period April 2013 to March 2014

There were 5483 hours of support delivered by neighbours across West Suffolk and South Norfolk.

Of these hours – 4430 hours (81 %) were devoted to providing companionship

The remaining 1053 hours comprised domestic, gardening, shopping, driving, dog walking, pet therapy and carers post death visits (19 %).

4.3 Other evidence

Anecdotal evidence provided informally through hospice neighbours and coordinators demonstrates the value of the service to our wider aim of creating **compassionate communities** and contributing to social capital in our local neighbourhoods.

Neighbours have reported that they feel much better equipped to deal with death and serious illness in their family and local setting, as a result of volunteering in this way. They are much more able to talk about matters associated with life limiting illness and dying in normal conversation and have a much greater awareness of the support services available

in the community as a whole.

In addition, the knowledge and awareness passed on to neighbours has in turn been passed on to others not involved in the service, enabling them to feel more confident about helping a neighbour who is facing death. In one case, one of our hospice neighbours visiting a bed-bound patient found that, once it was known that the service was involved, the next door neighbour of that person immediately began to offer more practical help knowing that there was a back up service and other support in place if needed.

Chapter Five Key learning points from our experience

In this chapter, we take the opportunity to share with you some of the key learning points from our experience of developing Hospice Neighbours.

5.1 Managing the risk

This has been an important area. Our approach from the outset has been to take a balanced approach based on a ***community enabling model***. We have sought to minimise the need for rules, regulations and procedures which can get in the way of timely and compassionate service provision. However we have always had neighbour and patient safety and welfare at the heart of what we do.

Sticking to a community enabling model rather than a medical model has been challenging at times, but it has served us well. As we have developed this approach we have had to answer a number of key questions. We share these with you together with our answers to these questions to help you think through the issues and develop solutions if you are contemplating a scheme such as this.

5.2 Frequently asked questions

5.2.1. How prescriptive should we be about what our neighbours do for their patients?

We decided at the outset to set some boundaries around tasks that we do not expect neighbours to do rather than being overly prescriptive about what they can and cannot do.

We don't normally expect neighbours to do the following:

- i. Personal care and hygiene
- ii. Lifting the patient or heavy loads
- iii. Administering medication of any type
- iv. Counselling or advising

However, in extenuating circumstances we suggest to our neighbours that they work within their own boundaries of comfort, dignity and safety and take a common sense approach.

If it becomes clear that a neighbour is doing more than anticipated in one area e.g. taking the patient to the toilet or performing some element of carer duties, then we monitor the

situation through the coordinator to ensure that they stay safe and continue to work within their own comfort zone. Neighbours are given information about other agencies in the local community who provide regular and ongoing personal care and cleaning services and are encouraged to signpost these services to their patient if necessary.

5.2.2. What do we do about neighbours transporting patients and paying expenses?

We insist on additional checks being in place if a volunteer neighbour uses their car to transport patients, requiring evidence of insurance, an MOT certificate for the car they are using, their driving licence and information of any relevant changes in circumstances. We also have a policy on reclaiming expenses from the hospice which we ask all volunteers to adhere to and coordinators monitor this to ensure that any journeys are not excessive.

5.2.3 How far do we go in assessing patients in their home environment before we match them with a neighbour?

Again our response to this has been to take a common sense approach so that the service can flow quickly and efficiently.

The majority of referrals are known to the hospice so we already have information about the patient to help us. Where a referral is received from outside the hospice and we do not have any health details or information about the patient's home environment, our volunteer coordinator will usually arrange an introductory visit before the patient is matched with a neighbour.

We also train our neighbours to assess certain risks on their first visit and to refer back to their coordinator if they have concerns. We give our neighbours training on manual handling, basic hygiene, risk assessment, lone working, handling money and offer equipment such as plastic gloves to use in case of an emergency.

5. 2.4 How we handle emotional risk and endings

The *death of a patient* can cause distressing emotions or trigger painful memories for a neighbour. Our volunteer coordinators are trained to offer basic support in these circumstances and monitor how the neighbour feels. This may involve meeting over coffee to offer support. Some neighbours ask for some time out before being matched with another patient, others want to get back to visiting as soon as possible.

If a neighbour remains very distressed, then the hospice counselling service or bereavement team may be accessed.

Another area of emotional risk is the *ending of a relationship* in situations where the patient is still alive, for a variety of reasons. An ending may be initiated by a neighbour, causing feelings of guilt or contributing to emotional 'burn out' if not dealt with sensitively. It can also be initiated by a patient who just feels that they no longer need the service. This might lead to feelings of failure or rejection on behalf of the neighbour and may need careful handling.

5.2.5 How have we managed the relationships with clinical staff?

Every effort was made to communicate the details of the new scheme to other hospice staff. However, in common with other new volunteer schemes, it has taken time to build confidence in the scheme. We are pleased to say that the service is now widely accepted and trusted as a very valuable part of what the hospice offers.

It has also taken some time for us to demonstrate to partners in the health service including GP's that we offer a safe and reliable service for their patients to. Ongoing communication is necessary to keep the service in 'front of mind' for busy clinicians.

Hospice Neighbours reflects a social model of palliative care through the development of a service which has sought to revive a more traditional cultural system of community support which is so clearly of value in terms of patient experience and wellbeing.

5.2.6 So what if anything has gone wrong?

We are pleased to report that very little has gone wrong to date over the time the service has been in operation. There have been several cases where neighbour /patient relationships have not worked out and one or two cases where we have had to let neighbours go from the service for particular reasons connected to behaviour or attitude. However the number of exceptional cases has been very small.

5.2.7. What about neighbour turnover?

Though relatively low, turnover does mean that there is a need for ongoing recruitment of new neighbours to both maintain and grow the service.

Some volunteers have remained with us from the outset, whilst others come and go for a variety of reasons. Sometimes they develop other commitments and others just find that they naturally need or want to move on to other things. They may also move on to employed work or volunteering work in another community support setting having enjoyed their experience with us, adding further to the local pool of social capital.

5.2.8. Dealing with peaks and troughs in the service.

We have noticed that there have been clear times when the demand for the service has outstripped the supply of volunteers, such as December and January, as well as times when there have been volunteers who cannot be matched with patients due to lack of demand. Both peaks and troughs can lead to frustration on behalf of employees who support the service as well as volunteers and patients. The situation needs to be constantly monitored so that those patients and carers in most need are given priority. As we build up more data over time, trends in the pattern of need will become more apparent.

Chapter Six And finally...

6.1 The Future

Our hope is for the scheme to be managed by a progressively lighter touch from the hospice, to the point where ownership of the service could be assumed more thoroughly by the community itself and the hospice gatekeeping role would greatly diminish. This could mean

more self referrals made directly to coordinators, by families, by church groups, by diverse village voluntary groups, health centres and others aware of need in their locality. The hospice role would become a back stop, chiefly for support, training and recruitment. At this point Hospice Neighbours would have achieved its aim of adding to the social capital of the community of West Suffolk.

6.2 Contact details

We do hope that you have found this case study helpful and that it has inspired you to think about how you could set up something similar in your area.

The aim of this guide and associated resources is to help answer the majority of your questions about our scheme. However if you do have any further questions or would like to find out more please do get in contact as follows:

Hospice Neighbours Scheme Coordinator: Kay Newman

Telephone: 01284 719638 Email: kay.newman@stnh.org.uk

6.3 Toolkit of resources

1. Hospice Neighbours Handbook
2. Referrals process (link)
3. Induction resources (link)
4. Quick set up guide (link)
5. Detailed breakdown of Hospice Neighbours Activity (link)

7. References

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