

Palliative Care in Heart Failure



A Collaborative Project to Improve End of Life Care
for Heart Failure Patients in East Kent.

Report Date:
30/06/10

Contents

	page
Executive Summary.....	3
Project objectives.....	7
Project methodology.....	8
Findings.....	11
Conclusions.....	22
Recommendations.....	23
Appendices.....	25
Annex	

Executive Summary

Evidence of unmet palliative care needs in heart failure populations is well documented. The needs are not just physical but psychological, social and spiritual as well.

Evidence shows that these needs are best met by introducing supportive care early, in end stage heart failure. To initiate a local response to this evidence for east Kent, a collaborative project was established. Working as partners, Kent Cardiovascular Network, Pilgrims Hospices in east Kent, Eastern and Coastal Kent Community Services and East Kent Hospitals Foundation Trust, Heart Failure Nursing Service Eastern and Coastal Kent Community Services assessed the current local situation and from the outcomes have attempted to make changes for the benefit of patients with heart failure.

Activities in assessing current practice have included service user involvement and the opinions and suggestions from related health professionals across East Kent. Recommendations for improvement and enhancement of the current service were taken from the findings of the project.

Objectives set at the start of this project have been achieved. It has been shown that through collaborative working, there has been an increase in the rate of appropriate referral numbers to palliative care from 35 patients in the year preceding the project to a total of 104 patients during the year that the project was running.

Recommendations include those that have commenced and those that will need further research to decide upon their viability.

These recommendations intend to improve the end of life care for the patient and carer living on a daily basis with the effects of heart failure.

It is suggested that a joint model of working continues, that the service users are 'listened to' and their wishes met. It was highlighted that professionals outside the hospice still have difficulty discussing end of life issues, Communication training could alleviate this problem.

It is recommended that the 'End of Life' heart failure pathway continue to be developed along with continued adoption and dissemination of the new ICD deactivation policy.

Referral criteria were felt to be too restrictive and it was recommended that the qualifying criteria were removed making this more 'needs' led.

The project team recognised that many heart failure patients were elderly and therefore it was imperative that links were made with this area of speciality. A training programme was set up predominantly for nurses and this it is felt, now needs to extend to doctors, especially GPs who are those predominantly caring for this group of patients.

Of those recommendations that need more consideration are the need for an outcome measure/audit and the question of intravenous diuretics and the 'best' place for these to be administered.

Above all the continued promotion of the hospice as a place that cares for the 'living' as well as the dying patient will ensure that patients and their carers accept the support that is available to them, at the right time.

Introduction

In 2008 Pilgrims Hospice approached the Kent Cardiovascular Network regarding help in a collaborative project focussing on Heart Failure and End of Life Care

Discussion had already taken place with NHS Eastern and Coastal Kent regarding establishing palliative care arrangements between Pilgrims Hospice, East Kent university Hospitals Trust and The primary Care Trust. The emphasis of this was establishing multidisciplinary teams in order that a collaborative model of care could evolve.

A project initiation document was presented to the Cardiac Board and agreement was given for the project to be established. £40,000 was awarded to Pilgrims Hospice for the establishment of the project

It was intended that a project manager would be recruited to lead the project for one year and that this would be a senior nurse. However due to recruitment difficulties another solution was sought, which was that funding, initially supplied for one senior nurse to work across the three Pilgrims Hospice sites, would be split equally across all three sites to secure the release for 2 days per week of existing Clinical Nurse Specialist(CNS) time for 1 year to progress the initiative. This was to be the CNS who already had a special interest in non cancer and end of life work.

The following is an evaluation report of the 12 month project that has been taking place in East Kent.

Project Team

Keith Duffy – Clinical Nurse Specialist Pilgrims Hospices (project lead)

Jane Thackwray – Principal Nurse Cardiology

Adrienne Bean – Network Service Improvement Manager

Jan Thirkettle – Clinical Nurse Specialist Pilgrims Hospices

Acknowledgements

The project team would like to thank the following for their participation, help and support with this project

The Kent Cardiovascular Network

Karen Edmunds. Communications and engagement manager. NHS Eastern and Coastal Kent

Simon Fisher Auditor Pilgrims Hospices east Kent

Paula Evans Nurse Director Pilgrims Hospices east Kent

1. Project objectives

At the commencement of the project the partnership set out the following objectives. It was proposed that these objectives would be met by collaborative working between the Cardiology and Heart Failure Nurse Specialist teams and by Specialist Palliative Care doctors and the Hospice Clinical Nurse Specialist teams. With the hospice and hospitals Trust being multi site and closely linked to distinct localities in the community setting, it was envisaged that this would enable relationships and clinical input to be worked up locally. The collaborative approach was assumed to be the best way to ultimately mainstream appropriate and effective outputs which would also support the Pilgrims Hospices strategy to increase equity of access for patients, through undertaking more work with non cancer related groups at the end of life. The objectives for the project were;

- Build effective working relationships between the hospice, Lead Cardiology Consultant, GP with special interest in cardiology and Specialist Heart Failure Nurses
- Establish a training programme for access by professionals for best practice palliative management of end stage heart failure management patients
- Demonstrate an increase in appropriate referrals to the hospice for patients with a primary diagnosis of heart failure.
- By the end of 12 months establish a weekly joint palliative heart failure management clinic, if this has been evidenced as the most appropriate way forward.
- Provide regular specialist palliative care input into the forthcoming heart failure multi- disciplinary meetings
- Provide an end of project report for stakeholders/stakeholder Boards

2. Project Methodology

In order to achieve the project objectives work commenced to identify activities designed to inform the project team of the current situation. In particular, where services would appear to be lacking in line with best practice. Thereafter, the design of the project evolved in an iterative way, ensuring it was 'locally grown' and developed in a meaningful manner for patients and professionals alike. Project activities included:

2.1 Workshops

Three workshops were held in total. The project commenced with an initial half day workshop in May 2009, launched by the Kent Cardiovascular Network. This provided initial thoughts and plans for the future of the project. A further workshop was held at six months in November 2009 where referral pathways were discussed and the project team gave an update on progress to date and what was still to be achieved. This event was attended by the Lead for National Improvements in Heart Failure. A third workshop intended to map the patient's journey prior to the project roll out was held in March 2010. A final celebration of work achieved was held in the summer of 2010.

2.2 Training-

Initial reciprocal training was given by Heart Failure Nurse Specialists and Clinical Nurse Specialists involved in the project, to improve understanding of each other's roles. It was important to understand what aspects of care each professional grouping had responsibility for and that that this was understood by the patient, carer and professionals alike. Community Matrons also received a training session on palliative care.

2.3 Job Shadowing

Undertaking job shadowing facilitated relationship building for both the Heart Failure Nurse Specialists and the Clinical Nurse Specialists. This exercise clearly highlighted patients that were appropriate for referral to palliative care services that would otherwise not have been referred. It began the process of learning for the Heart failure Nurse Specialists in "when" to refer, a concern that was highlighted by them during the initial training. It taught the hospice Clinical Nurse Specialists how to run clinics efficiently and increased knowledge of heart failure and the medications used. Job shadowing was a catalyst that began to increase numbers of appropriate referrals to the palliative care services. Pilgrims Hospice Clinical Nurse Specialists made contact with their local GPSI's and clinics were observed.

2.4 User involvement

To involve those using local services, the approach to user involvement took the forms of both questionnaires and focus groups.

Questionnaires- 60 questionnaires were distributed to patients and 60 questionnaires were distributed to carers. Patients were identified by the Heart Failure Nurse Specialists and questionnaires were distributed in person (Annex) Responses were received from 43 patients and 30 carers.

Focus Groups- Three groups were held in November 2009. One group was held on each Pilgrims Hospice site. These involved eight patients and nine carers. They were hosted by the Communications and Engagement Manager, NHS Eastern and Coastal Kent

Community Services (ECKCS) and supported by a Pilgrims Hospice Clinical Nurse Specialist and one ECKCS Heart Failure Nurse Specialist. Each group was held at a different time of day to allow for as many patients/carers to attend as possible. It was ensured that those attending did not know the nurse specialists that were present. Report (Annex)

2.5 Case Reflection

Case reflections have been an ongoing process. In the early days of the project case reflection clearly highlighted a need for an Implantable Cardioverting Defibrillator (ICD policy) that would ensure safe practice and in particular timely deactivation of the devices. Reflection of a “what had gone well” as well as “what could be improved” approach as a regular scenario began to highlight ways in which both the Clinical Nurse Specialists and Heart Failure Nurse Specialists could change practice in the interests of patients.

2.6 Multi-Disciplinary Meetings (MDM's)

The development of MDM's had been a vision for development for some time prior to the project. Opportunity therefore presented to roll out the project alongside the establishment of the planned MDM's. In July 2009 the first heart failure MDM was held at Queen Elizabeth Queen Mother Hospital. This was attended by a specialist palliative care doctor and Clinical Nurse Specialist. Similarly the multi-disciplinary meetings at William Harvey Hospital commenced in February 2010. They have yet to commence at Kent and Canterbury Hospital. There is no date for this at the time of reporting. Learning from these will be documented in the “findings” section, later on in this report.

2.7 Joint Heart Failure clinics

A pilot for these commenced in January 2010. They were planned in all three Pilgrims Hospice areas, with clinics both in the hospices and at satellite locations to enable patients to access these as easily as possible. Due to the progressive nature of heart failure and the speed with which a patient can deteriorate and subsequently improve, these clinics have not been the success it was hoped that they would be. It has however prompted the project team to explore alternative methods of providing a timely and cost effective intervention that gives the patient effective care. The outcome of this will be discussed in the section “findings”. Joint visits to patient's in their own homes has continued throughout the project.

2.8 National Event

Representation from the project team attended the “Ask me what I want conference” and a National Improvements process mapping event. These provided further helpful networking and discovery about what was happening in the speciality of heart failure nationally.

2.9 Training programme

A programme entitled “Best practice management for end stage heart failure patients” has been developed for professionals working both within the hospice, primary care and acute settings. Two training days were held predominantly for Clinical Nurse Specialists who will be continuing to implement the work already started. The Clinical Nurse Specialist days were very well evaluated and will be opened up when next held, to other hospice staff. The first training day for external professionals will occur in summer 2010 (Appendix 1)

2.11 Data collation

A variety of data was collated from 01/06/08 -31/05/09 and compared to data collated from the 01/06/09- 31/05/10. Aspects compared were as follows in the table below.

- Referrals
- Mean time from referral to death/discharge
- Reason for referral
- Referrer
- NYHA Classification on referral
- Symptoms
- Palliative Care interventions accessed
- Advanced Care Planning
- Ability to attend a clinic
- Average age on referral
- Admissions to hospice inpatient unit

3. Project Findings

There were a number of positive outcomes from the project. These outcomes are outlined below.

3.1 Joint Working

A model of joint working was adopted throughout the project between Pilgrims Hospice CNS and the Heart Failure Nurse Specialists. This resulted in:

- Building of effective relationships.
- Improvement in understanding of roles, scope and limitations.
- Sharing of expertise
- Joint decision making (including the patient) to improve their outcomes.
- Shared learning

3.2 User Involvement

Both the questionnaires and the focus groups gave a valuable insight into the perception service users had of the care and support that they received. Recommendations for improvement were made and acted upon.

Actions

- The booklet “Caring Counts” was adopted by the Heart Failure Nurse Specialists as this gave all the information that service users had felt that they were lacking.
- The patient held record book was reviewed by the Heart Failure Nurse Specialists to include space to add the names of the professionals involved in their care and their contact details.
- Improving knowledge of health professionals in delivering palliative care in heart failure was recommended. As a consequence a process mapping event was held and this has consequently led to the development of the local end of life heart failure pathway (Appendix 2)

The questionnaires and focus groups highlighted the benefit that service users gained from the Living for Today programme that is run on all three sites of Pilgrims Hospices. Especially beneficial was the Breathlessness Management group. The Caring with Confidence group was also highlighted.

Figure 1 - illustrates an interim review of the effectiveness of non-pharmacological breathlessness management for the patient at Pilgrims Hospices. The tool currently used to measure effectiveness of the intervention is the “Modified Borg”

Limitations included unavailable data from one site, and as shown 28.25% scores were not completed as the patients were not well enough to comply. Figures would indicate that whilst 38.5% patients scored an improvement in their breathlessness symptom, 28.25 % remained unchanged. It must be remembered that patients with life limiting illness such as heart failure can deteriorate during an intervention and this can lead to an increase in symptoms. These figures therefore uphold current evidence that it is advisable to use a quality of life tool alongside a numerical rating score. It is the intention of Pilgrims Hospices breathlessness management group to implement this.

Borg Scores July09- May 2010

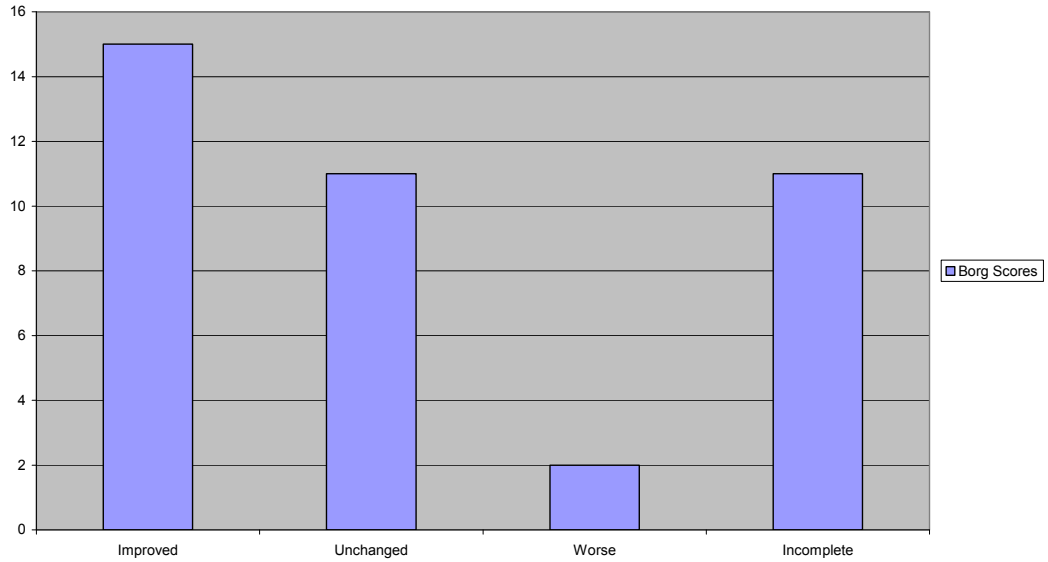


Figure 1 - n= 34

Data collated during the project shows that the most frequent symptom complained of was breathlessness. Figure 2. shows that whilst twelve symptoms are documented here, in total thirty six different symptoms were documented, complained of by patients at first contact with a Pilgrims Hospice Clinical Nurse Specialist. This upholds current evidence that a patient with heart failure has as much, if not a higher symptom burden than a patient with cancer.

Symptoms

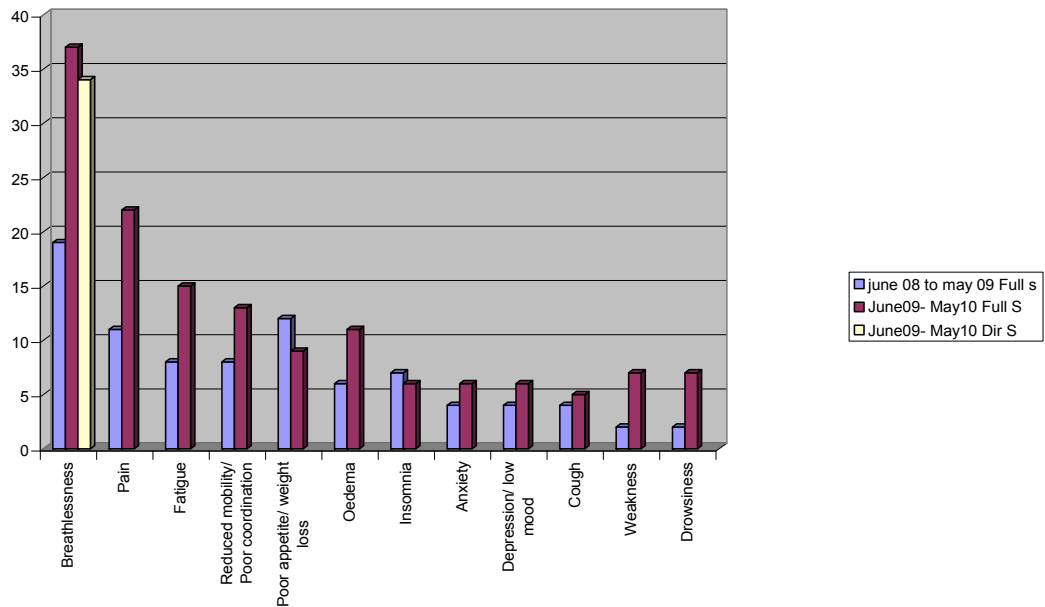


Figure 2 - n= 139

3.3 Case Reflection

This was an important method of highlighting aspects of care that were not effective for the service user. A distressing case (appendix 3) was reflected upon that proved the need for a policy ICD deactivation that would improve on current practice and promote safety. This was undertaken and completed. A new policy has now been ratified.

3.4 Professional Involvement

Professionals were engaged in a number of ways throughout the project. The three workshops proved an effective method of bringing together as many interested parties as possible. As a result of the workshops, issues have been discussed and relationships have been strengthened. The referral process has been discussed and it was highlighted that the additional referral criteria to hospice services was felt to be too complicated and could deter referrers.

One Cardiology consultant reported a change in practice regarding the use and management of ICD devices in response to cases reviewed during heart failure multidisciplinary meetings.

Care processes were mapped using the six key steps of the national end of life care pathway. Results have been combined with other project consultation outcomes and feedback from many professionals that were unable to attend the process mapping workshop to formulate a local End of Life Care Pathway in Heart Failure (appendix 2). Relationships have been strengthened as a result of the heart failure MDM's. The heart failure project was developed in conjunction with these. With the growing awareness that these have given to the appropriateness of "when to refer" the service user has received more timely referral to palliative care services both in hospital and community (71% of community referrals during the year of the project were not urgent compared to 47% in the year preceding it) Figure 3 shows in part why patient referrals have become more specific with a drop of 33% in referrals that had no reason for referral documented and only three referrals documented as inappropriate.

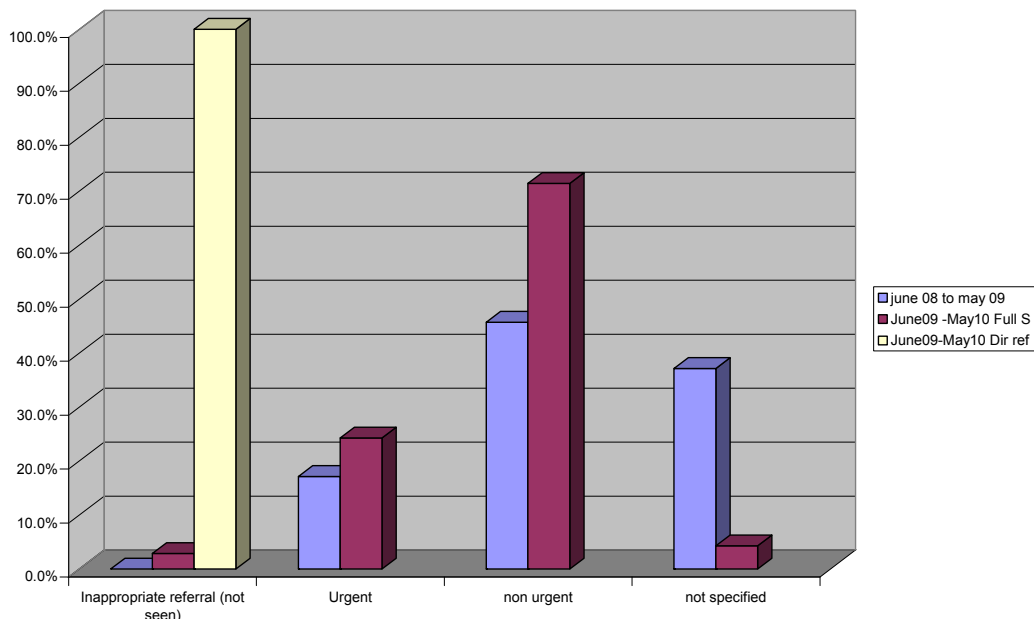


Figure 3 - n= 139

3.4 Training Programme

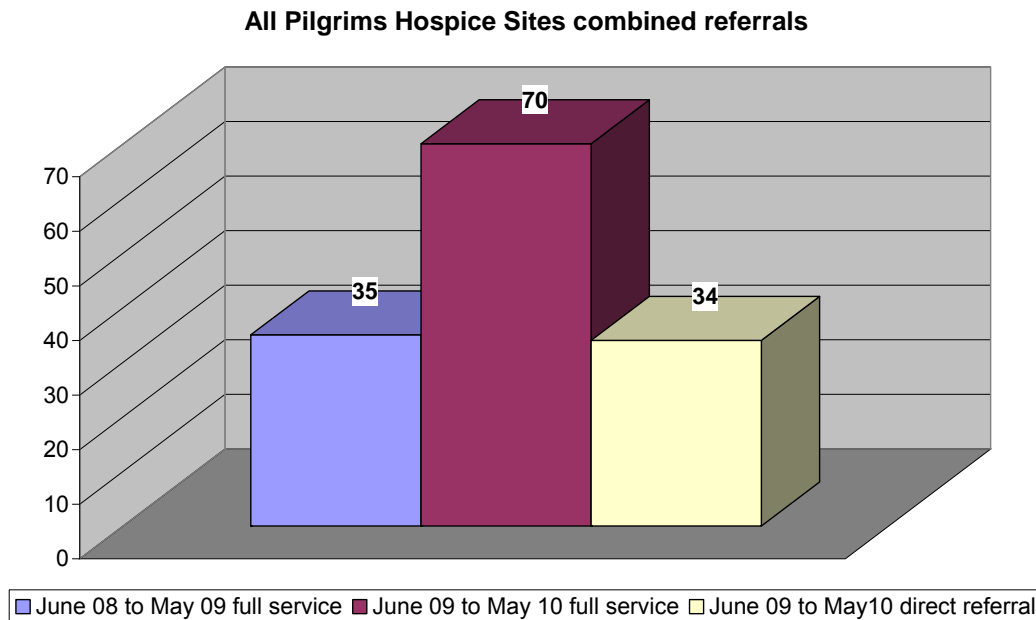
The training programme held at Pilgrims Hospices for all Clinical Nurse Specialists was very well evaluated by the attendees. The professionals that attended have by the content of the day been given the knowledge and importantly the confidence to care for the service users who are living with end stage heart failure. They will also have an increased ability to take non pharmacological interventions for breathlessness to those at home that are too unwell to attend the breathlessness group, supporting therefore service users regardless of performance status. A training programme for external professionals is to be held on 28/06/10 and therefore cannot be evaluated at this point.(Appendix 1)

3.5 Referrals to Palliative care services

The number of appropriate referrals to palliative care services during the year of the project has increased from 35 in the year preceding the project to 104. The dual route of referral to Pilgrims Hospices has ensured that 34 patients have been able to take advantage of a service that they would otherwise either not have been appropriate for, or would have declined. The dual routes of referral are:

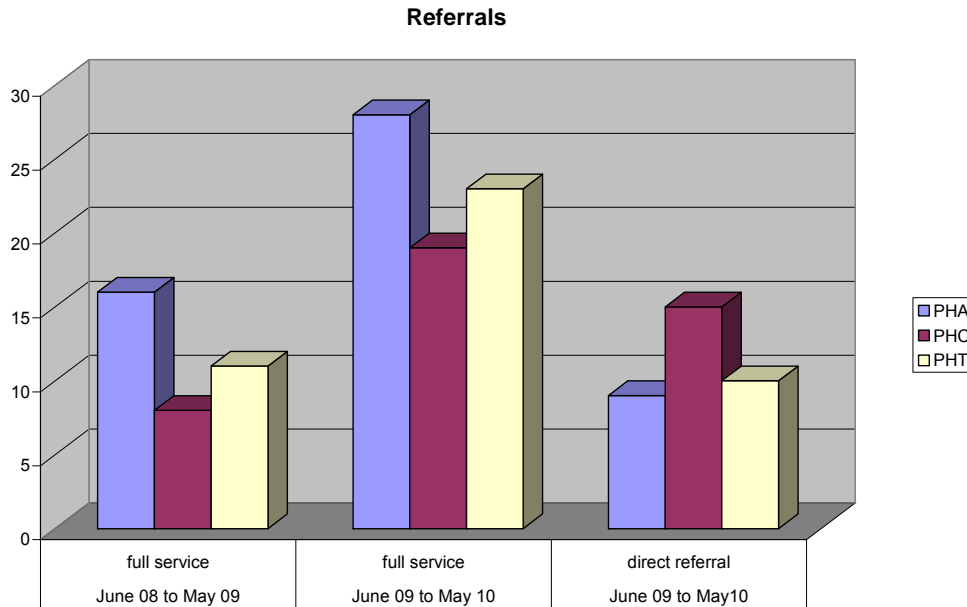
1. Referral to the full service (multidisciplinary approach)
2. Direct external referral for the Living for Today programmes (appendix 4)

Figure 4 illustrates the increase in referral numbers.



n= 139 Figure 4

This can further be broken down to demonstrate the referrals in each of the three Pilgrims Hospice geographical areas. Figure 5.



n= 139 Figure 5

Feedback from professionals at workshops indicated that the unpredictable nature of heart failure where the disease trajectory is peppered with sudden deterioration requiring emergency hospital admission, coupled with a typically short dying phase presents a potential barrier to knowing 'when' to refer.

Highlighted also, was the difficulty that professionals experience in having the confidence and skills needed to discuss referral and the issues that this may raise.

It is anticipated that with joint collaboration, MDM's (both Heart Failure MDM's and Gold Standards Framework meetings) and advantage being taken of the Advance Communication Skills training available to health professionals in East Kent, that these issues will be addressed to the benefit of the patient.

It has been important that positive learning has come from the project in areas that were not as successful as the collaborative had anticipated they would be.

3.6 Joint Heart Failure/Palliative care clinics

Prior to the pilot of the joint heart failure clinic it had been expected that there would be potential benefits for the service users. It had been felt that:

- Visible joint working gains patients' confidence
- Overcomes patient apprehensions re hospice involvement
- 'One stop shop' approach to address disease management and palliative needs in one assessment.

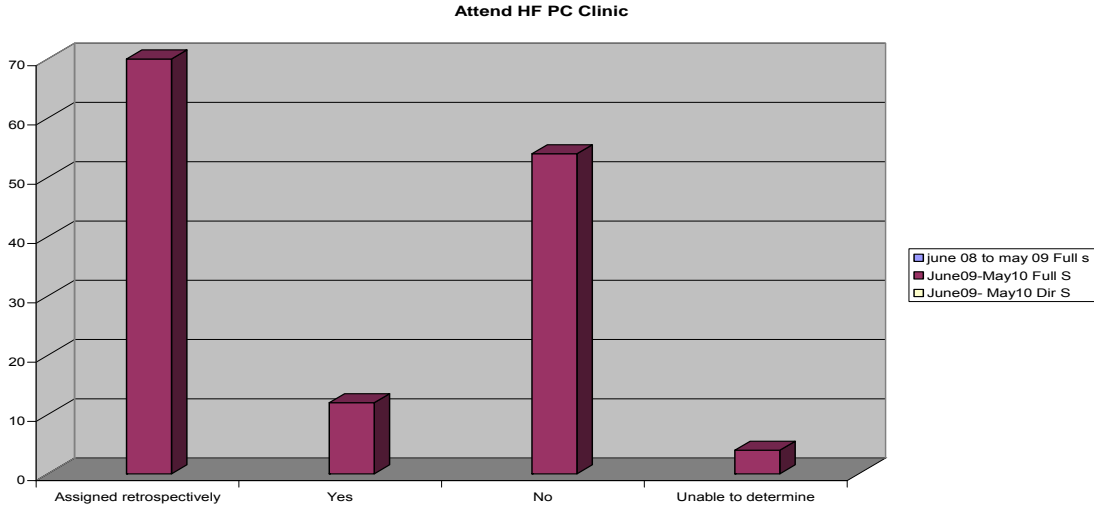
The format for the clinic was as follows, the Heart Failure Nurse Specialist would begin with symptom review and medication optimisation. The Clinical Nurse Specialist would continue with their palliative care assessment. It was envisaged that these patients would be seen as a new referral for the palliative care Clinical Nurse Specialist.

Consideration was given to the large geographical area and satellite clinics were set up in Tenterden, Folkestone and Dover. Deal was also considered a suitable location for a clinic. It was anticipated that this would enable patients to attend more easily. Clinics were also held at each of the three Pilgrims Hospice sites.

Referral and consequent attendance was poor. This appeared to be as a result of the nature of heart failure. Of the 4 patients that were referred there was only one that was seen as a new palliative referral. The remainder of patients become too unwell to attend the clinic, resulting in an urgent first visit for the Clinical Nurse Specialist at home.

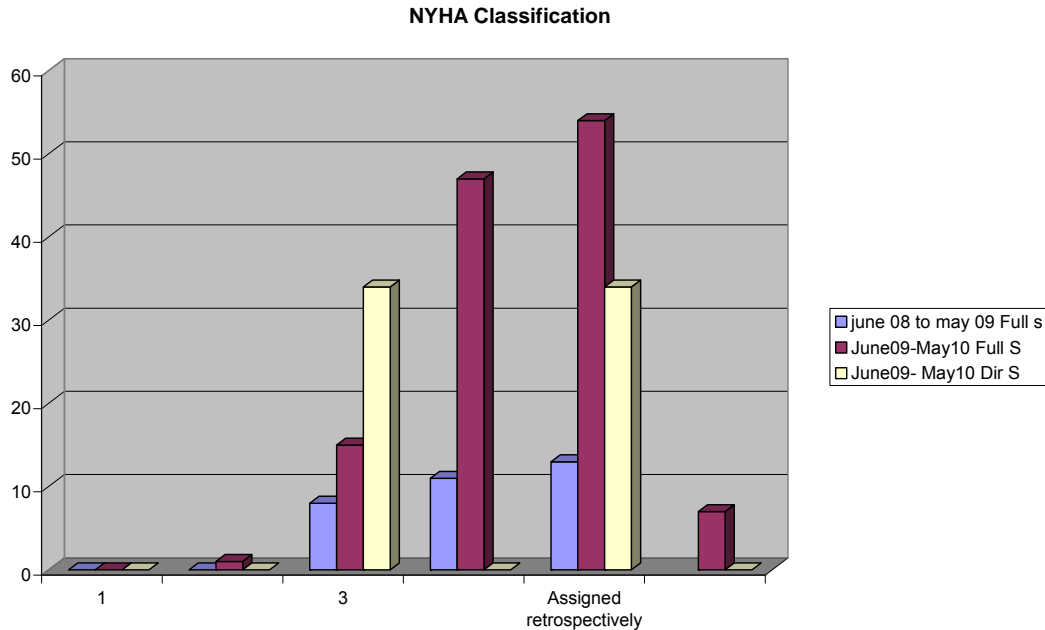
A retrospective review of the patient referrals was carried out to determine how many patients during the year of the project would have been able to attend a clinic (this data does not include patients referred for the Living for Today Programme via direct referral)

Figure 6 illustrates this. It can be seen that in one year only 10 patients would have been appropriate to attend a clinic as a new palliative care referral.



n= 70 Figure 6

As a result of the above, it was decided to assess the New York Health Association Class (NYHA) of the patients referred. As this was not always documented on the referral retrospective assignment of class was used where necessary. This proved to the collaborative(project team) that as the majority of patients were classed NYHA 4 it was the condition of the patient that was necessitating a home assessment. Figure 7.



n= 104. Column 6 shows those that were unable to be retrospectively assigned. Figure 7.

As there were patients, albeit in small numbers that would benefit from a clinic the collaborative discussed ways in which this could be achieved in a time and cost effective manner, that still brought benefit to the patient. A decision was made to pilot nurse led palliative care clinics in Tenterden and Pilgrims Hospice Ashford that both the service users and Heart failure Nurse Specialists could attend when appropriate. It was also decided to 'open up' the clinics to 'follow up appointments' It is too early to gather data to prove that this method is effective. Nurse led new referral clinics are also being run in Pilgrim Hospice Thanet where heart failure patients can be seen. Again it is too early to prove that this method is effective for the patient with heart failure.

3.7 Macmillan Gold Standards Framework GP practice meetings-

It became apparent when attending meetings as part of the palliative care Clinical Nurse Specialist role that not all GP practices were considering placing non cancer patients on their palliative care registers. It must be stressed here that there is no data to support this. As part of the project the collaborative and their colleagues have informed professionals at these meetings about the project and highlighted patients that were suitable to be placed on the register. This advocates early identification of care preferences and CPR status, maintaining a register of palliative patients whose needs are discussed and reviewed at regular GP-led multidisciplinary meetings. It includes also the sharing of this information between key services including out of hours providers.

The meetings have also been attended by the Heart Failure Nurse Specialists and Community Matrons and have been helpful in determining key workers.

3.8 Data Collection

The importance of collecting data has been recognised during the project. It is impossible to achieve accurate figures if this is not maintained.

3.9 Outcome measures

Time has been taken to consider which tool would be the most effective to measure outcomes of the project in terms of “what benefit” the patient has experienced from the project. This has not yet been decided. Advice from fellow professionals will be sought.

3.10 Crisis Plans

Service Users displayed concern during the focus groups that there was a lack of communication between care settings. There was the need at each hospital A&E admission to have to repeat their history. There were also questions on why their care and symptom management plans did not follow them into hospital.

Professionals wanted to improve the communication in this area and along with the service users wanted to reduce the turn around time where the admission was for palliative management of fluid overload by intravenous diuretics (see recommendations)

Discussions between the collaborative took place. Initially it was debated whether the existing patient held records (community cardiac service care record) could be utilised to document crisis management plans, care preferences and CPR status with the addition of a brightly coloured sticker that could alert professionals (ambulance crews, A&E, hospice, care home staff) to the documented crisis information within. Feedback however from professionals noted that previous attempt to use hand held records failed. This was because plans were not updated or effectively documented. The consensus now is to await the implementation of long term conditions care plans and develop these to meet this need.

Although various findings have been referred to in this report, there are other interesting outcome's from the data collated. It was felt that this data would give the collaborative information about the palliative care services used and needed by patients and carers living with heart failure. The following figures refer to this collation of data.

3.11 Referrals and admissions

Figure 8 indicates the admissions to Pilgrims Hospices and referrals to the Living for Today programme in comparison to the amount of referrals with a primary diagnosis of heart failure since 2007. It demonstrates the increase in referrals. It highlights also an increase in the number of admissions to the inpatient unit.

Referrals and admissions

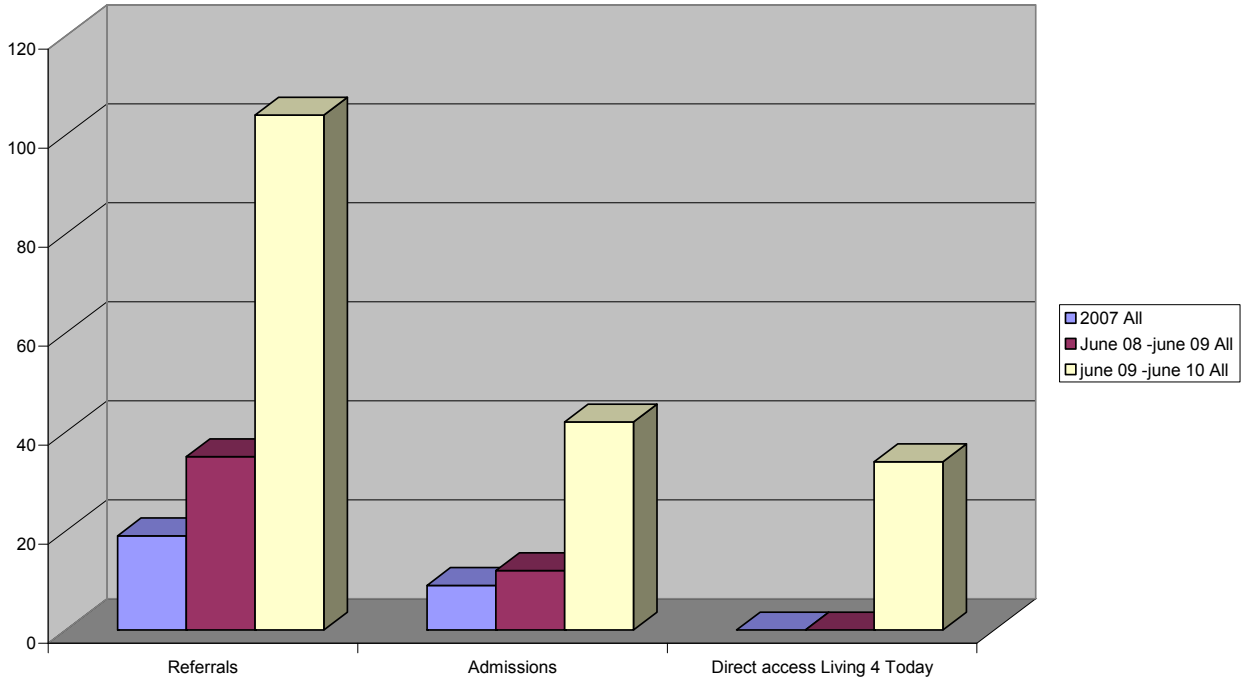


Figure 8 - n= 156

Figure 9 below shows a breakdown of the reason these patients were referred. It indicates that during the course of the project, reasons for referral have become clearer to the professional referring. This is due to the collaborative working model promoted during this time.

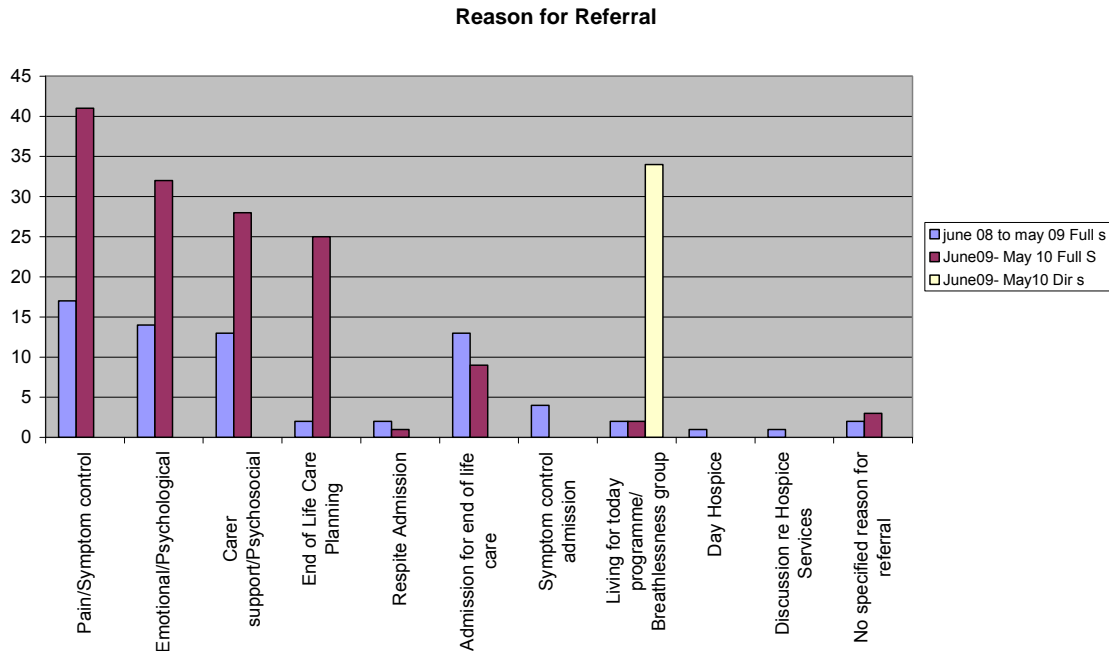


Figure 9 - n= 139

All patients accessed a combination of hospice services available. These services are tabled below.

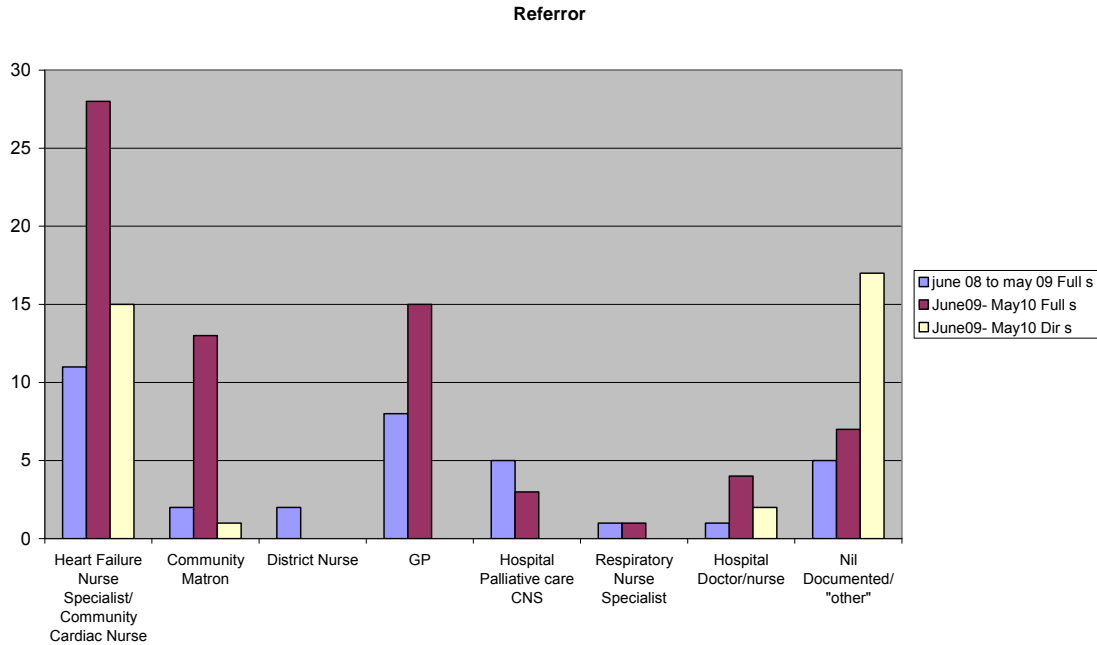
Palliative care team interventions accessed

Breathlessness Management Group

- Domiciliary visits CNS/Dr
- MDM
- CNS telephone calls
- Social Worker domiciliary/inpatient
- OPA/inpatient/hospital by hospice doctor
- Chaplain inpatient/Day hospice
- Bereavement support
- Counselling patient/carers
- CNS GSF meetings
- Living for today programme
- Carers Day
- Day Hospice

3.12 Referral information

The graph below demonstrates the professionals referring. Whilst the Heart Failure Nurse Specialists continue to be the main referrers, there has been a sharp increase in referrals from the Community Matrons. This is possibly as a result of training during the project but could also relate to an increase in collaborative working and therefore more insight in 'when' to refer. This could also apply to the increase in referrals from GP's.



n= 139 Figure 10.

Age on referral

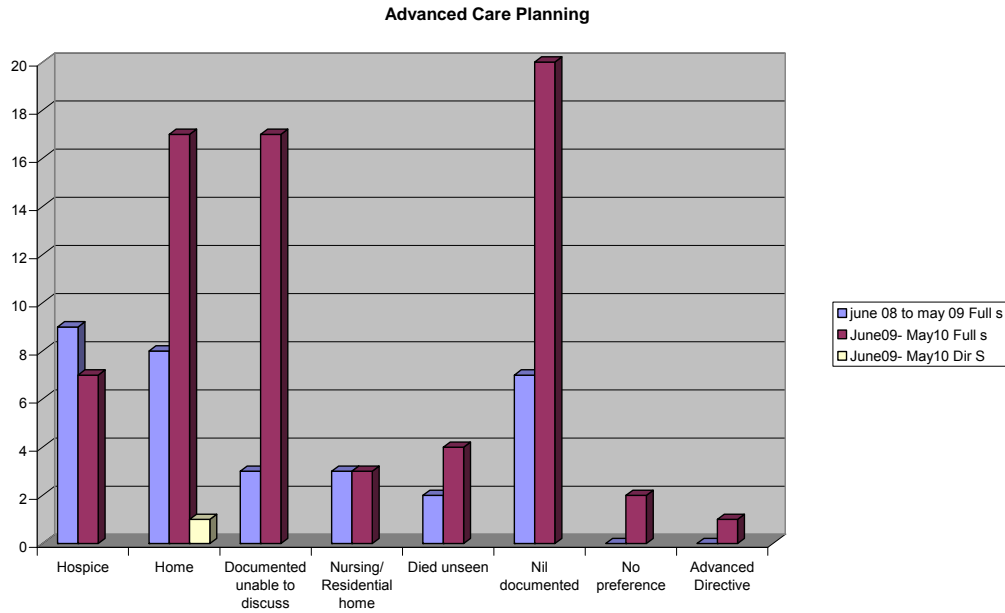
It was queried at Workshop three by a Cardiologist that he was unclear of the mean age of referral to palliative care of the service users. This was collated for the period of the project and the results are as follows:

Patients referred for the full service 81 years

Patients referred for the Living for Today Service 71 years

3.13 Advanced Care Planning

This is an important part of palliative care. Figure 11. below shows an increase in the number of heart failure patients wishing to die at home and a small decrease in those wishing to die in the hospice. It also highlights the amount of patients where nothing at all is documented concerning their wishes (see recommendations)



n= 139 Figure 11

6 Conclusions

This report brings together the objectives, outcomes, findings and recommendations from a nurse led project that ran over the period of one year 01/06/10- 31/05/10. It has highlighted areas of practice that have been beneficial to the service users. Unmet needs have also been identified. The objectives set have been achieved.

It has been shown that through collaborative working and promotion of palliative care services in East Kent, referral numbers have risen from 35 in the year preceding the project, to 104 in the year that the project has been running. These have been seen to be appropriate.

The collaborative has striven to benefit the service user by ensuring that there are more appropriate and timely referrals to palliative care. This will in turn ensure that there is equity of hospices services for heart failure patients.

Non pharmacological breathlessness management skills have been increased within the hospice clinical nurse specialist teams as has their knowledge through a new training programme.. This will ensure that patients can receive interventions from the first visit palliating the most prevalent symptom that heart failure patient's appear to experience.

Where initiatives have not been successful, alternative methods of achieving these have been considered and acted upon.

It is hoped by the collaborative, that the following recommendations will be acted upon in order that heart failure patients and their carers can expect an effective and holistic service.

7 Recommendations

7.1 Communication Skills

Encourage advanced communication skills training for all professionals involved in the assessment and care of dying patients utilising the available training programmes in East Kent

7.2 Local End of Life Care Pathway

Further the development of this. Ensure the engagement of professionals not yet involved (G.P's, District Nurses, Community Matrons, Out of Hours Providers, Ambulance services, Elderly care, A & E staff)

7.3 ICD Deactivation policy

Encourage dissemination of this across all sectors.

7.4 Referral Criteria

The collaborative would suggest a revision of the current Kent wide hospice referral criteria for patients with a primary diagnosis of heart failure. It would suggest removal of the additional qualifying criteria. This would enable the referral criteria to become more 'needs' led (Appendix5).

7.5 Continued promotion of hospice services/ referrals

This will enable as many service users as possible to benefit. It is also important to remind professionals how to refer. It is recommended that the Pilgrims Hospice Website is reviewed in order that it is easier to download the correct referral form. It is recommended that there be consideration to 'merge' the 'full' and 'Living for Today' referral forms to enable less confusion when referring to Pilgrims Hospice.

7.6 Caring Counts Booklet

Continue to provide information to patients and carers prior to referral via the Caring Counts Booklet which has been adopted by the Heart Failure Nurse Specialists.

7.7 Joint model of working

Continue this approach to care between all professionals involved in patient care. This is to include the Heart Failure MDM's. This model of working to be continued by all Clinical Nurse Specialists as the project closes.

7.8 Joint Heart Failure/Palliative Care clinics

To be piloted in the new format and evaluated for effectiveness both for the patient and the professional in November 2010 (after a six month pilot)

7.9 Elderly Care

Build links with the elderly care teams as the mean age on referral to palliative care is 81 years of age. It is known that there is a proportion of patients with heart failure over the age of 78 that may not have seen a Cardiologist or Heart failure Nurse Specialist.

7.10 Training Programme

This is recommended to be run for both internal hospice professionals and external candidates on a yearly basis. The first external training programme is to be held later in 2010. The date is yet to be set.

7.11 Outcome Measures

Further investigation is needed of appropriate evaluation tools for palliative care and collaborative interventions to demonstrate effectiveness of patient outcomes. The collaborative feels that this should incorporate a qualitative component. A qualitative tool will be added to the evaluation method for the breathlessness management programme.

7.12 Patient Engagement

The collaborative recommends that the questionnaires and Focus groups are repeated after one year to ensure that services develop in line with service users needs.

7.13 Audit

An audit to be performed with the overarching standard being 'Heart patients get the same access to palliative care as any other patient with a life limiting illness' The importance of collecting and recording data accurately needs to be stressed to those involved.

7.14 Intravenous Diuretics

The collaborative feels that it would be beneficial to the service user to investigate pre planned rapid intervention for crises. The aim would be to avoid a protracted hospital admission. Investigate the feasibility of intravenous diuretics being given in this scenario in hospice/ home/ day case settings. There is at present no data to demonstrate the numbers of service users needing this type of service. The collaborative is investigating other service providers who may provide a similar service.

Appendix 1

Session Training Plan for clinical Nurse Specialists

Two days were planned to ensure that the groups attending were small enough to facilitate discussion.

Aspects covered were:

Outcomes and objectives for the day

- To be confident when assessing and advising patients with end stage heart failure.
- To have a better understanding of what heart failure is.
- To understand the medications involved in the management of heart failure.
- To be able to manage the palliative symptoms that patients with heart failure experience.
- To be able to use non-pharmacological interventions in the management of the breathless patient.
- To be able to confidently “carry on” when the project finishes with aspects such as the MDM’s and joint clinics/collaborative working.

Session 1 An overview of the project and introduction to the day.

Session 2 ‘What is Heart Failure’ Lead Cardiac Nurse

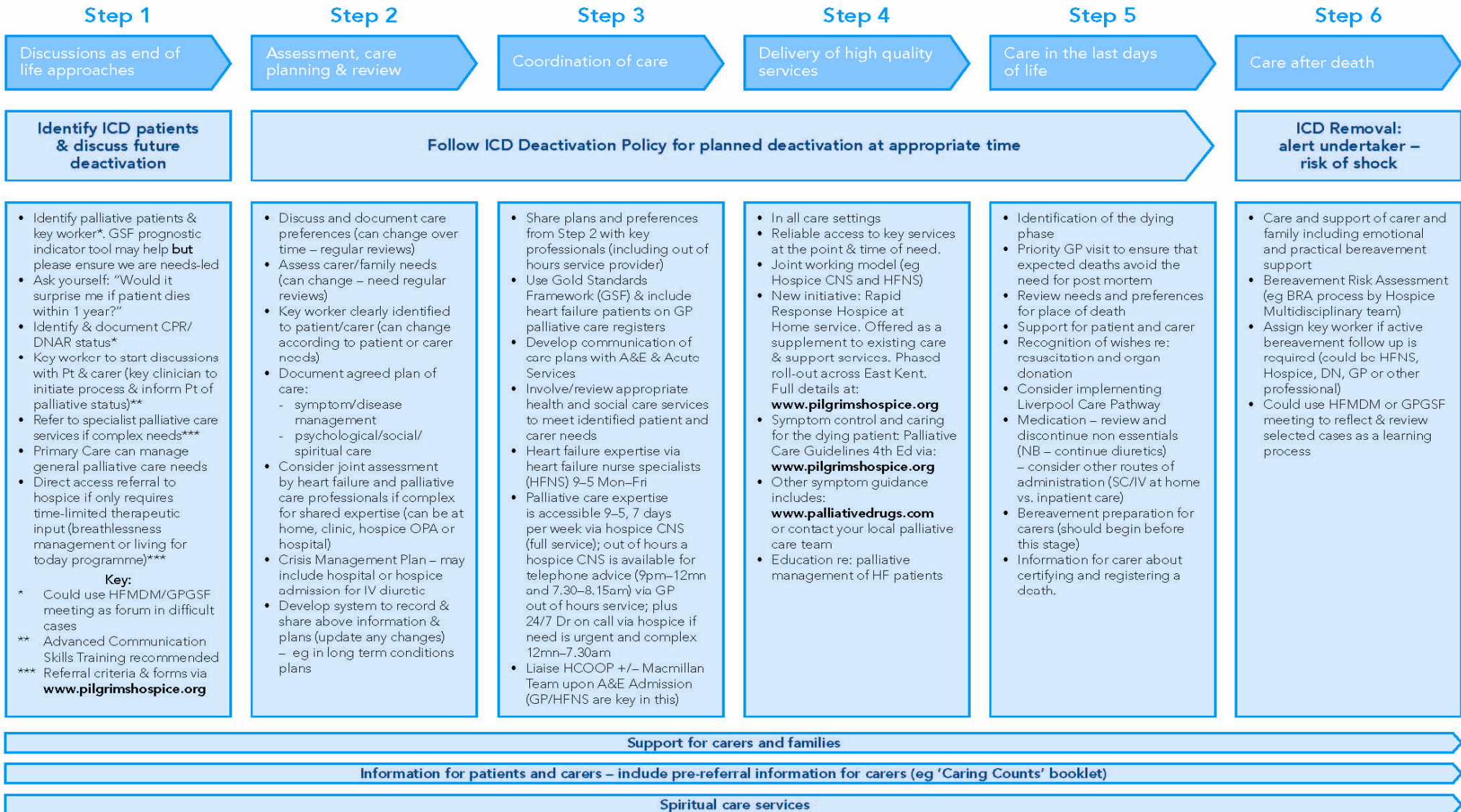
Session 3 Palliative symptom control in heart failure.

Session 4 ‘The way forward’5 Breathlessness Workshop

Appendix 2

END OF LIFE CARE PATHWAY IN HEART FAILURE

Adapted for use in East Kent by Pilgrims Hospices and Kent Cardiovascular Network
 Note: Key worker to co-ordinate pathway action points where no professional is specified



Appendix 3

Case reflection highlighting the need for an ICD policy

- Mr B is a 78 year old man.
- 2001 Myocardial infarctions x 6
- 2001 Coronary Bypass Graft
- 2007 Referred to Heart Failure Nurse Specialist team. Had a Medtronic Bivent ICD in situ which had fired over 30 times since insertion in 2001 and more than 4 times that year
- July 2008 Admitted with unmanageable VT- had VT ablation and x2 coronary stents inserted.
- May 2008 ICD fired. Following this he had increasing breathlessness and broke his foot in a fall. Optivol was alarming constantly.
- ICD continued to fire x4 in a three day period.
- Sept 2008 Admitted for ICD box change.
- End October 2008 discharged home
- Early November 2008 had 13 shocks in three days
- Cardiac technicians were unable to come out to deactivate ICD. Magnet left with patient

During the next three days the patient had x 18 further shocks. The patient applied the magnet himself and died instantly **Appendix 3**

Appendix 4

Living for Today Programmes Pilgrims Hospices in east Kent

These groups comprise

Healthy Living.

For patients to take part in a personalised exercise programme and learn about the benefit of a healthy lifestyle, symptom management, coping with fatigue, nutrition and diet, activity and exercise.

Breathlessness management.

Sessions can assist to improve quality of life improve understanding and the causes of breathlessness. Reduce admissions to hospital due to anxiety and help patients and families feel more in the control of symptoms.

Time to Create

To help patients to find different forms of self expression, stretch their imagination, get involved with new interests or pastimes and have enjoyment and fun.

Relax and Restore

To help patients learn to relax and find ways to cope more effectively with worry about now and the future, anxiety, stress, feeling low in spirit, depressed and coping with changes being faced.

Caring with Confidence

For those offering support and care to relatives or friends. Provides knowledge, understanding and advice about pain and symptom control, transfer and handling techniques, local resources, finance and benefits, diet and food preparation, illness and the future.

Appendix 5

GUIDELINES FOR REFERRAL TO SPECIALIST PALLIATIVE CARE

(All at the discretion of the referrer and in conjunction with clinical assessment)

CRITERIA FOR REFERRAL TO SPECIALIST PALLIATIVE CARE include

Patient and medical team (consultant or GP) aware of and agree to referral to specialist palliative care

Patient has complex physical, psychological or spiritual symptoms OR patient has expressed a desire for the hospice to be the Preferred Place of Care (PPC)

PLUS TWO OR MORE OF THE FOLLOWING:

1. Patient should be aware of the diagnosis of heart failure and have an insight into the irreversible and progressive nature of their disease, and be accepting of a palliative care approach

2. Advanced heart failure (New York Heart Association Grade 3 or 4* at discretion of health care team or cardiology team)

3. Anticipated last 12 months of life

4. Three admissions to hospital within the last 12 months with symptoms of heart failure despite optimal treatment



Heart Failure Service Questionnaire for patients and their carers

NHS Eastern and Coastal Kent Community Services

November 2009

Project Lead: Jane Thackwray, Head of Community Cardiac Services
Project No. PES/038/09
Report by : Helen Knope / Lesley Tune
Document Version: 2
Document Date: 09.02.10

CONTENTS

Executive Summary	3
1. Introduction / Aims	4
2. Methodology	4
3a. Findings – Patient Questionnaire	5
3b. Findings – Carer Questionnaire	14
4. Discussion.....	23
5. Recommendations and Conclusion	23
Action Plan.....	24
Appendix 1 Copy of Blank Patient Questionnaire	26
Appendix 2 Copy of Blank Carer Questionnaire	28
Appendix 3 Findings from Heart Failure Focus Groups.....	31

Executive Summary

1. Introduction / Aims

The Heart Failure Service is working together with Pilgrims Hospices to improve the care they provide to patients and their families at the end of life.

The questionnaires were designed to help the Cardiology Service identify what patients and their carers know about these services, whether they meet their needs and how future care can be improved

The Service also plans to run some focus group with the assistance of Karen Edmunds.

2. Methodology

The Service planned to hand out 60 patient and 60 carer questionnaires over a period of six weeks from early September to mid October 2009.

When patients/carers were asked to complete the questionnaires they were also asked if they wish to attend one of the focus groups.

33 copies of the carer survey were completed and 43 copies of the patient survey.

3. Recommendations and Conclusion

The return rate for responses was good and was typically reflective of the heart failure population with regard to age. The current problems/symptoms being experienced by patients were reflective of large scale research projects. Most patients were aware that they had a life limiting disease, however only 48.8% had discussed end of life issues. For those that had discussed end of life, this was mainly with family members and only 24% had had discussions with a health professional.

There seemed to be an awareness of the hospice and the services it could provide, however it was surprising that large numbers of responders did not want information regarding Lasting Power of Attorney and Advance Directives. Whether this is due to a lack of knowledge and understanding of the subjects or whether this reflects true feelings is difficult to interpret.

Patients and carers felt well supported, disclosing typically reported fears of being alone and losing independence, but also reported positive responses of wanting to live for today.

The carers were typically in the over 60 age bracket, mainly female and mostly retired.

The findings of this survey were used to determine themes for 3 focus groups held during November 2009 for patients with Heart Failure and their carers. The responses from the survey were upheld by the Focus groups and the action plan below is in response to both engagements. The findings from the focus groups are shown in Appendix 3.

4. Action Plan

A copy of the action plan can be seen on pages 24 and 25 of this report.

Heart Failure Service Questionnaire

1. Introduction / Aims

The Heart Failure Service is working together with Pilgrims Hospices to improve the care they provide to patients and their families at the end of life.

It is already possible for people with heart failure to be referred to the hospice. The Living for Today programmes cover a variety of issues including breathlessness, caring with confidence, stress reduction and healthy living. It is also possible to access care for complex physical and psychological needs such as symptom management, social support and respite care.

The questionnaires were designed to help the Cardiology Service identify what patients and their carers know about these services, whether they meet their needs and how future care can be improved

The Service also plans to run some focus group with the assistance of Karen Edmunds.

2. Methodology

Karen Edmunds worked with Jane Thackwray, Head of Community Cardiac Services, to produce the patient and carer questionnaires. Karen Edmunds also consulted with a patient with a heart condition and their carer on the design of the questionnaires and their suggestions were incorporated. Helen Knope, Patient Experience Survey Manager, was also asked for her comments.

The Service planned to hand out 60 patient and 60 carer questionnaires over a period of six weeks from early September to mid October 2009. Patients and carers were provided with Freepost envelopes to return the completed questionnaires to Karen Edmunds.

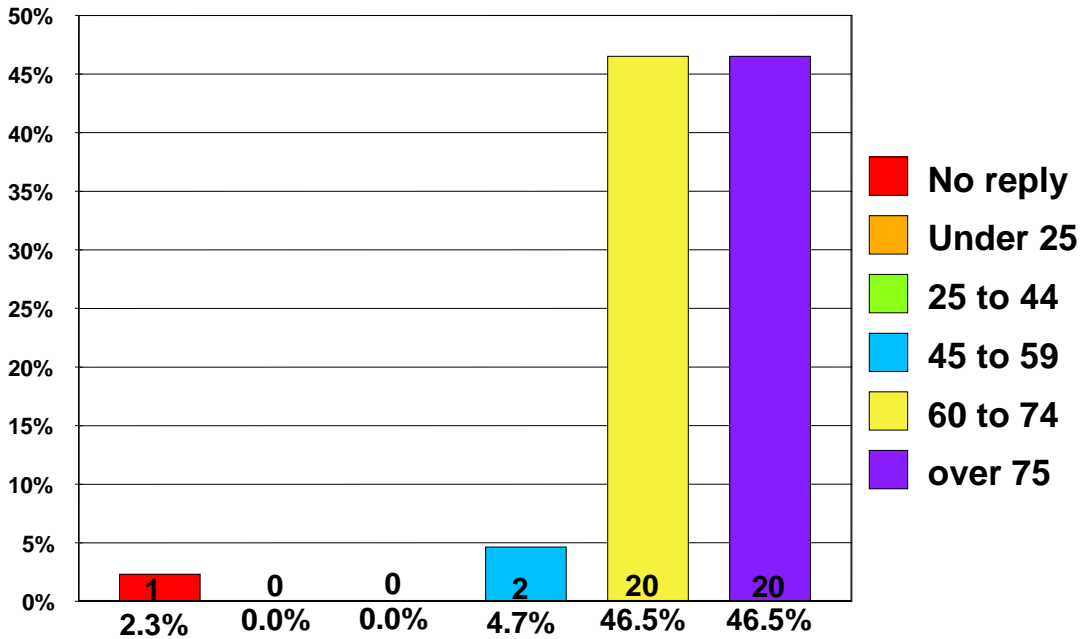
33 copies of the carer survey were completed and 43 copies of the patient survey.

When patients/carers were asked to complete the questionnaires they were also asked if they wish to attend one of the focus groups.

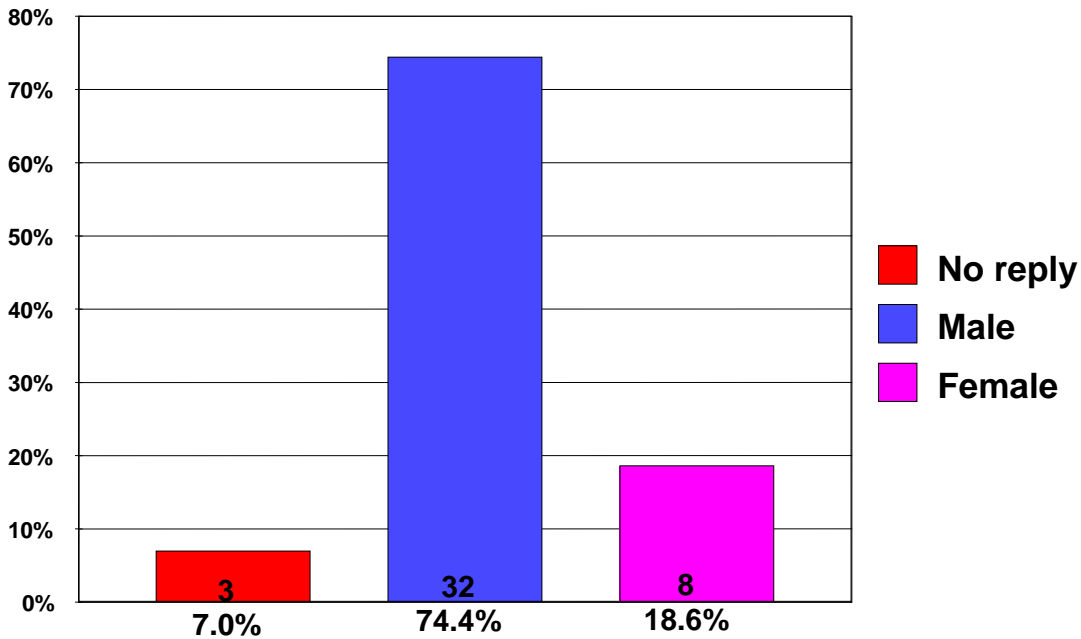
Karen Edmunds planned to devise some focus group questions to build on feedback from the questionnaires.

3a. Findings – Patient Questionnaire

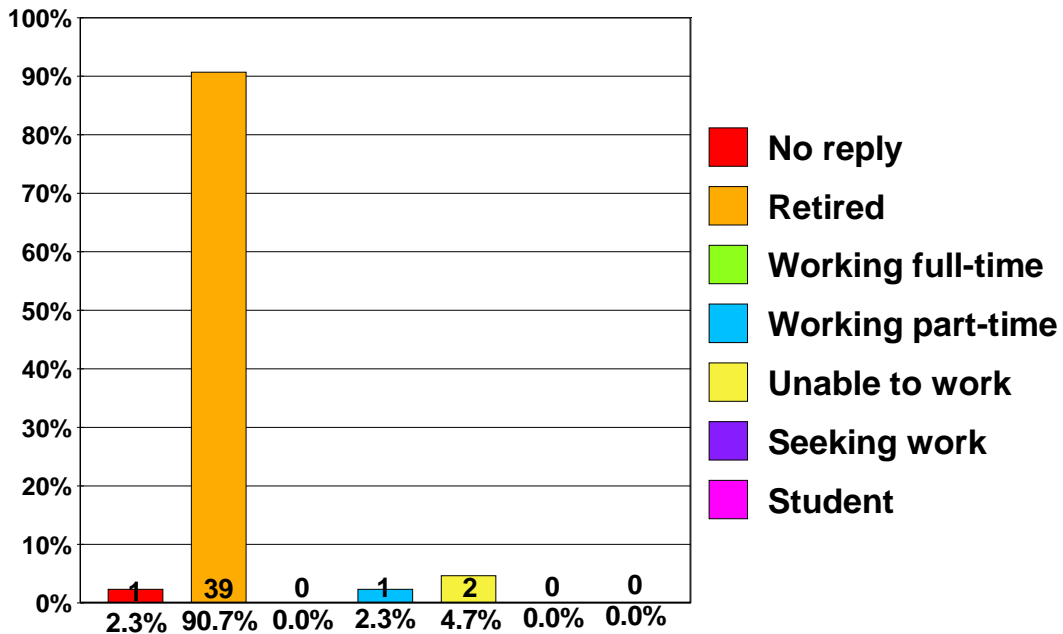
1. Age Group



2. Are you male or female?



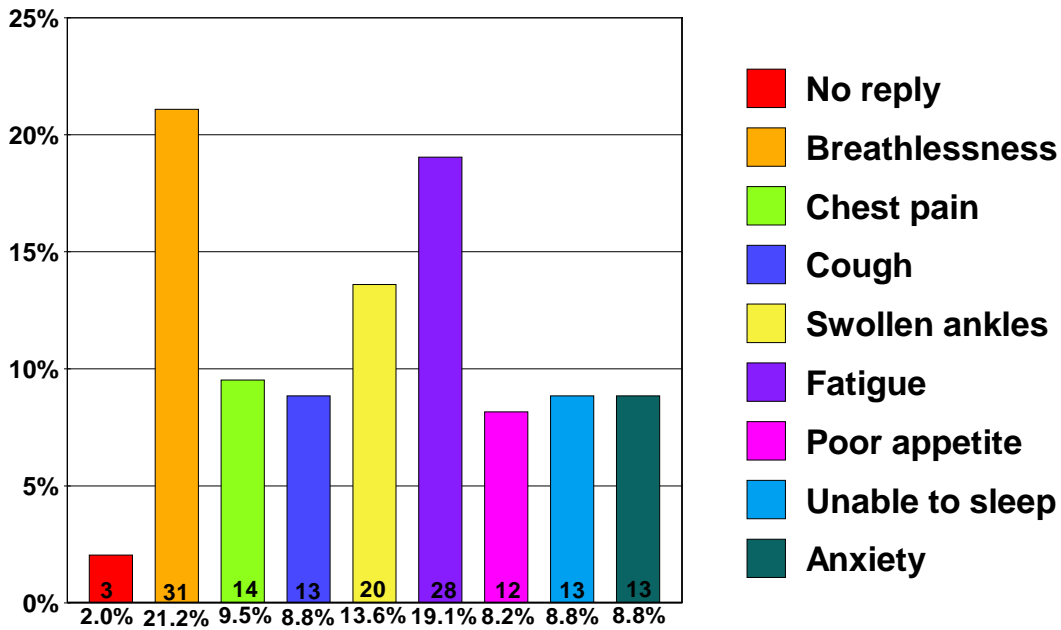
3. Which best describes you?



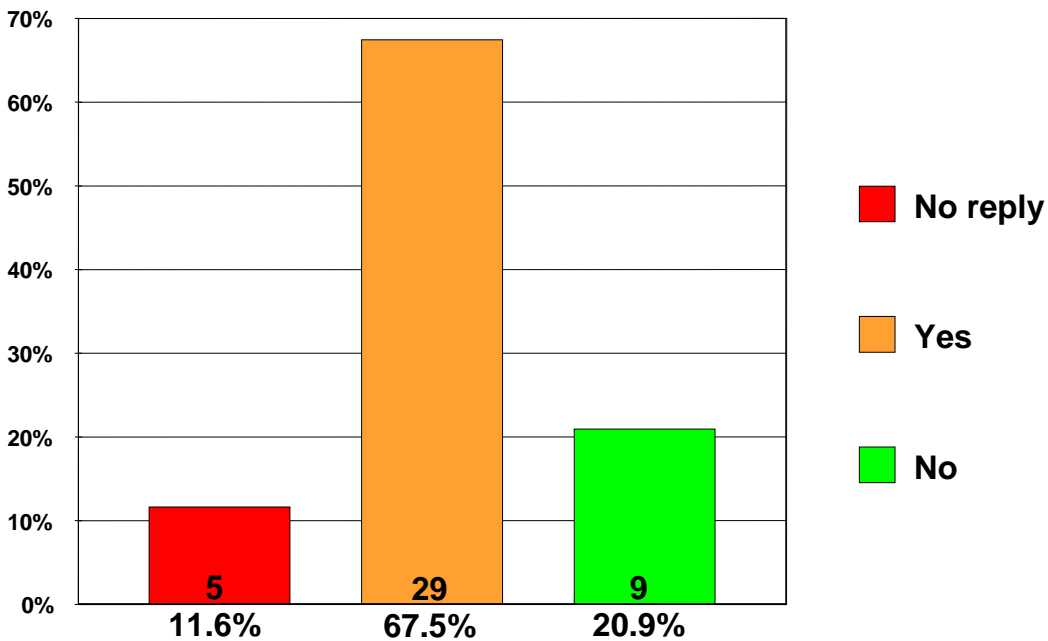
4. How long ago were you diagnosed with heart failure?

- 6 months
- 7 months
- 10 months
- 1 year x 4 patients
- 15 months
- 18 months x 2 patients
- 2 years x 3 patients
- 2 1/2 years
- 3 years
- 3 1/2 years x 2 patients
- 3-4 years
- 6 years
- 6-7 years approximately
- 8 years
- 9 years x 2 patients
- 10 years
- 12 years x 2 patients
- 13 years
- 15 years
- Approximately 20 years
- 30 years

5. What are your current problems?



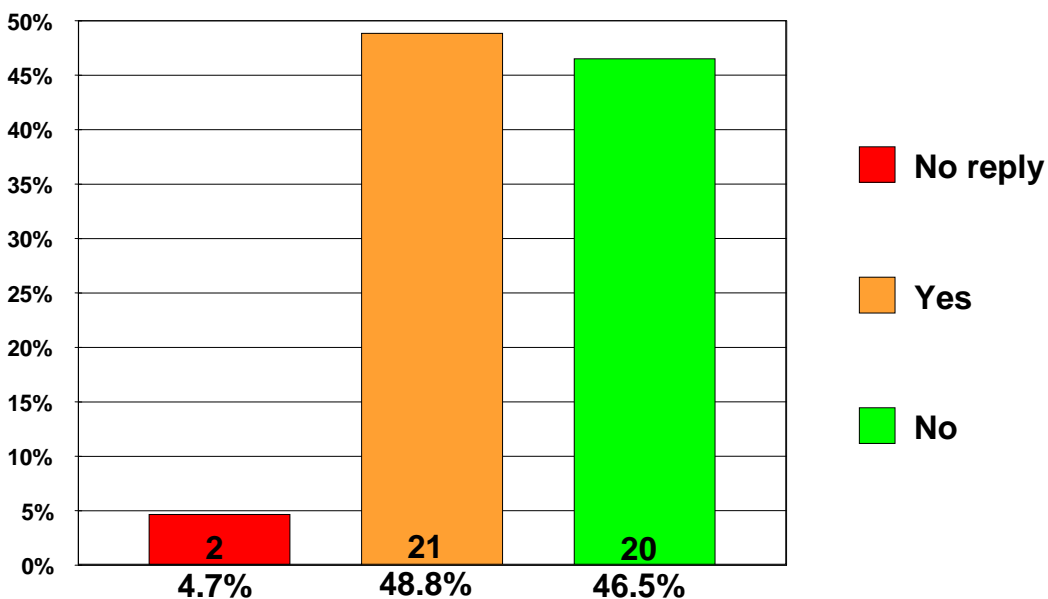
6. Do you feel your life will be limited due to heart failure?



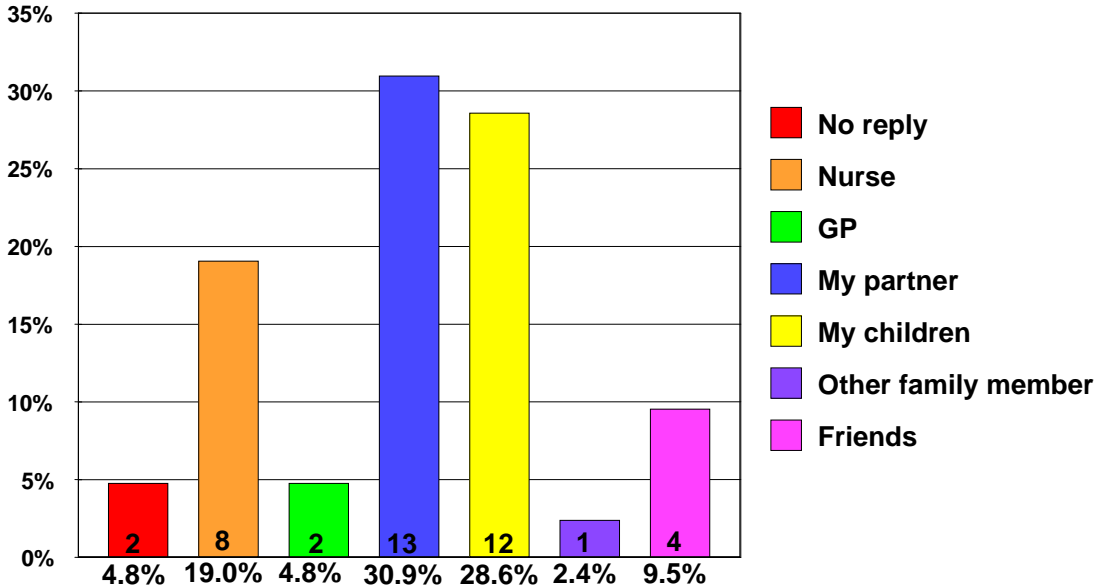
If yes, how does that affect you now?

- Mo more than my life is limited now - heart attack, diabetic, hypotension, depression.
- I miss not being able to do the things I used to, i.e. driving, walking, etc, which limits my social life and not being able to do things for myself and need assistance.
- Reduced activity.
- Inability to go on holiday.
- It's just that I can't do what I used to.
- No energy - get very breathless so cannot do anything.
- Breathlessness and fatigue.
- Unable to walk without getting breathless, now use a walking stick. Find being out in cold windy weather also makes me breathless. Get tired easily, have to pace myself when doing things in the garden and in the home, and live on my own.
- Slows me down.
- Very restricted what I can do, always been very active.
- Lack of stamina (difficulty exercising and hard to diet). Cold weather restricts movement outside.
- Unable to do things that I enjoyed. Housebound. Unable to read books etc, due to blindness.
- I'm limited to what I can do physically.
- It is more limited by age (96).
- As I am over ninety I take each day as it comes on the basis there may be other factors.
- Gardening and household chores.
- Physically and mentally.
- Limited lifestyle.
- My life is limited as I have a left ventricular assist device fitted into my abdominal wall. This is as a bridge to transplant, but although I no longer have heart failure episodes, I do find my daily life restricted.
- Reasonably mobile in home but lack of mobility outside.

7. Have you discussed end of life issues with any health care professionals or family members?



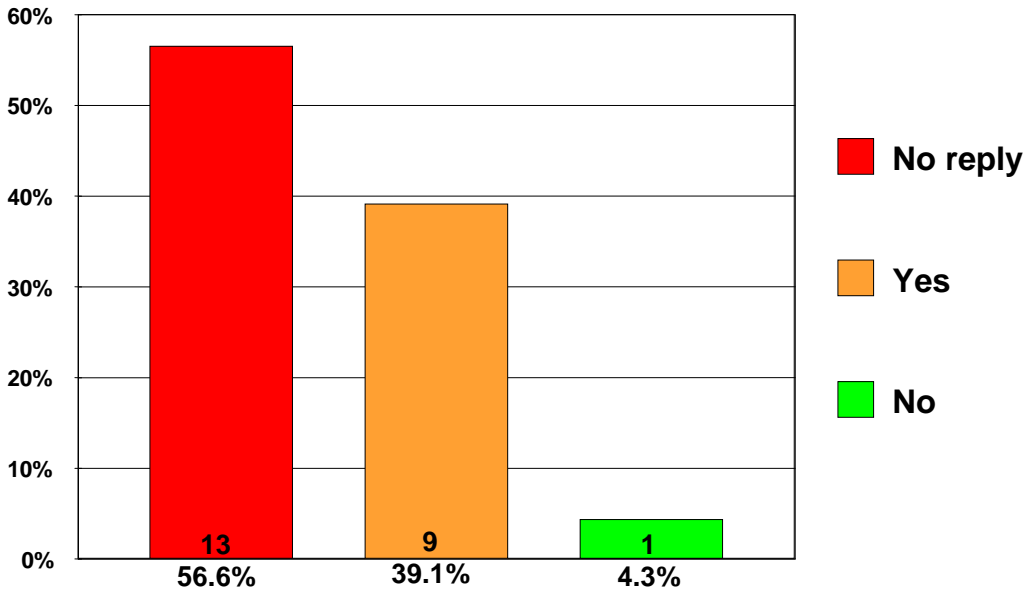
8. If yes to Q7, who did you discuss end of life issues with?



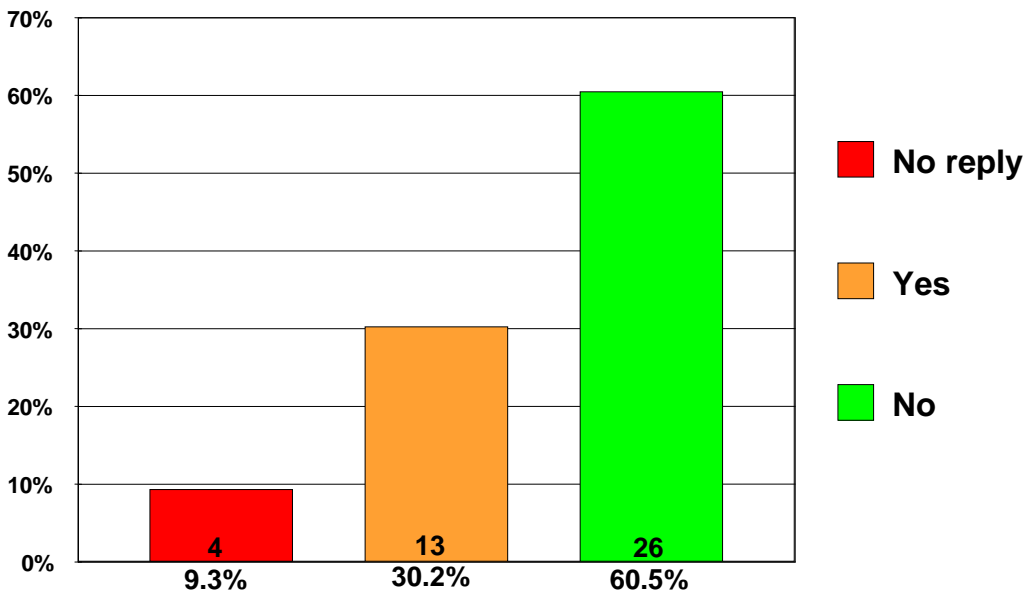
If you discussed end of life issues with any health care professionals or family members, how did it make you feel?

- In control, to make my wishes known.
- More content with them and myself.
- Discussing these issues makes the subject of 'end of life' problems more approachable, and hopefully will help those close to me to cope when I am gone.
- The discussions have been in general terms, not particularly related to heart failure.
- Relieved that I have informed my nephew (my executor of my will) where to find my will and how I want my funeral arranged.
- It was hypothetical, but at least it has been mentioned.
- Depressed.
- Depressed.
- Very unsettled.
- Angry with my lot. Frightened, worry about my wife.
- Does not affect my feelings.
- Neutral

9. If you discussed end of life issues with a nurse or your GP, do you think it was done at an appropriate time?



10. Have you been referred to the hospice team?



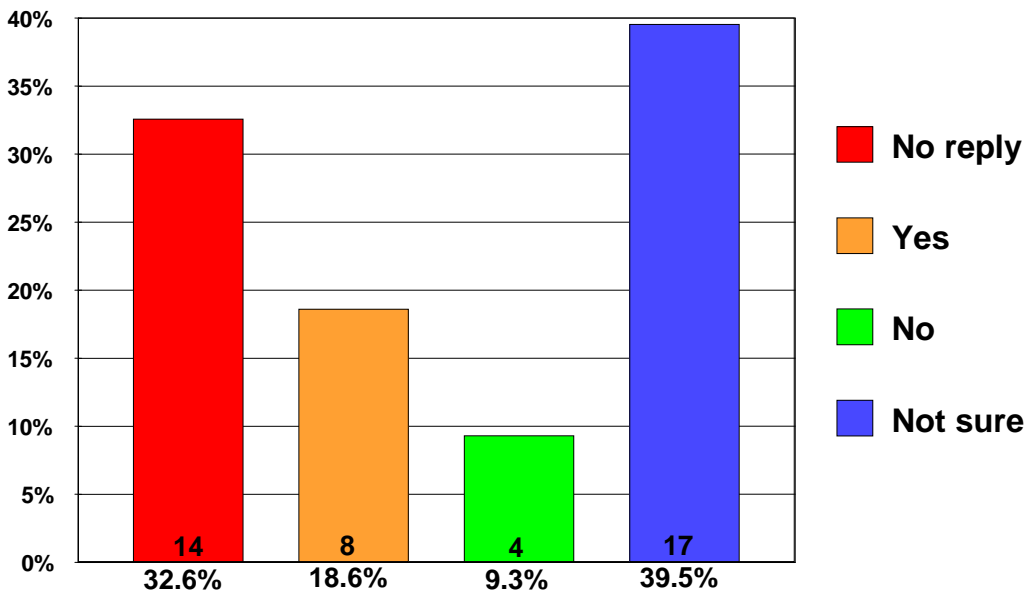
If you have been referred to the hospice team, what services have you found the most helpful?

- Breathlessness Management Programme, Day Hospice.
- Breathlessness.
- Breathing course.
- Breathing classes.
- Breathlessness Clinic. Lymphoedema Clinic.
- Going to the Day Centre and having Respite Care. Only social outing I have and have transport provided.
- Have not attended yet.
- Day Hospital.
- All.
- Haven't got that far yet.
- I was referred to the Hospice Team last year and had discussed 'end of life' in the Hospice. I then had the LVAD transplanted and did attend the Hospice once a week for a day after the operation, but felt that wasn't appropriate for me at that particular time.

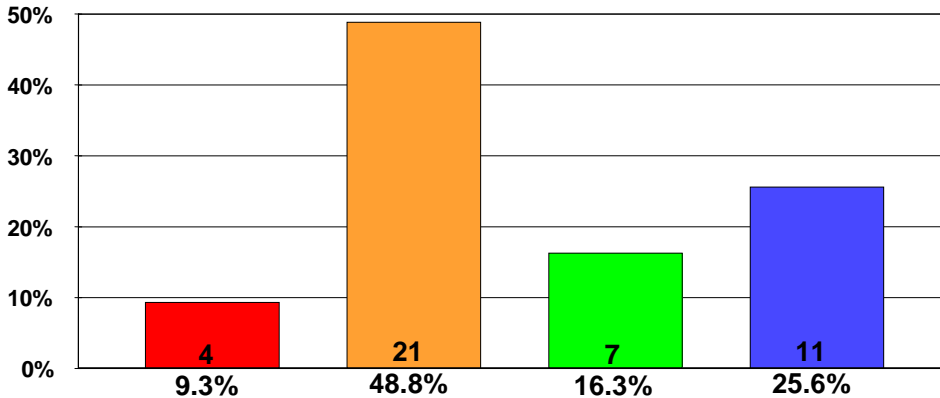
If you have been referred to the hospice team, what services have you found the least helpful?

4 patients said 'None'.

11. If you have not been referred to the hospice would you like support from the hospice team in the future?

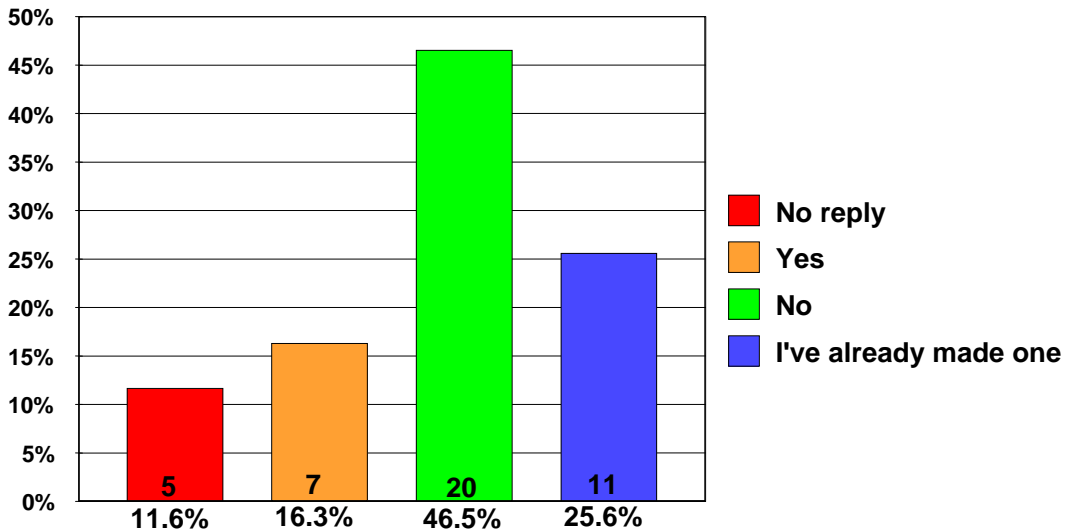


12. Which of these statements best describes your feelings about receiving service through the hospice?



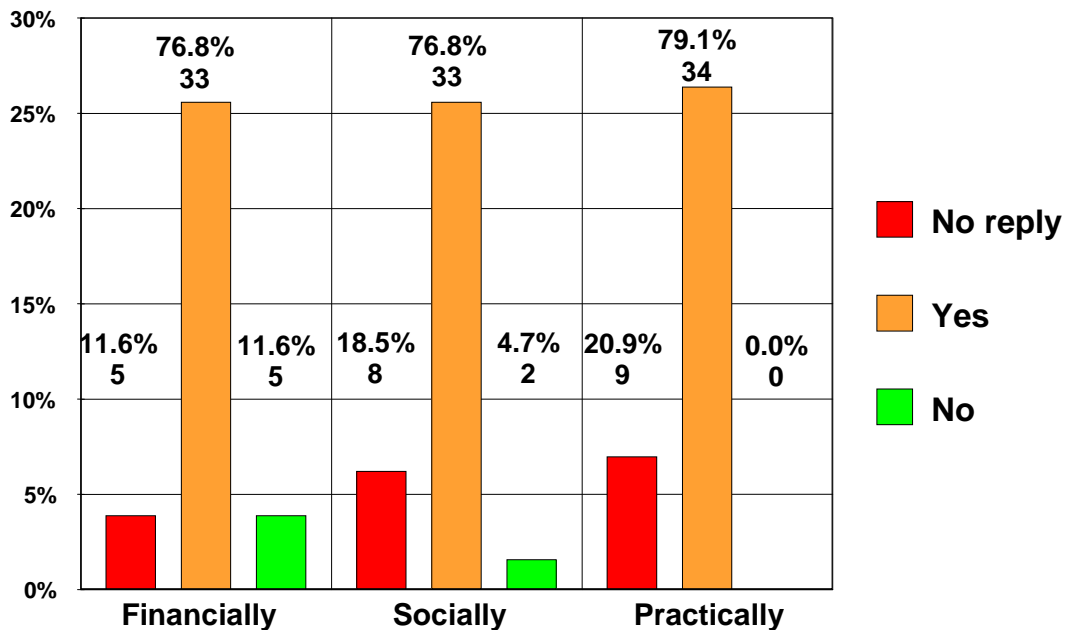
- No reply
- It's fine - I understand that they can support me and my family
- At this stage I'd rather not have contact with the hospice
- I'd like to know more about what they can offer before I make a decision

13. Would you like information about making a Lasting Power of Attorney or Advance Directive, in order to help to plan for the future?



- No reply
- Yes
- No
- I've already made one

14. Do you feel adequately supported?



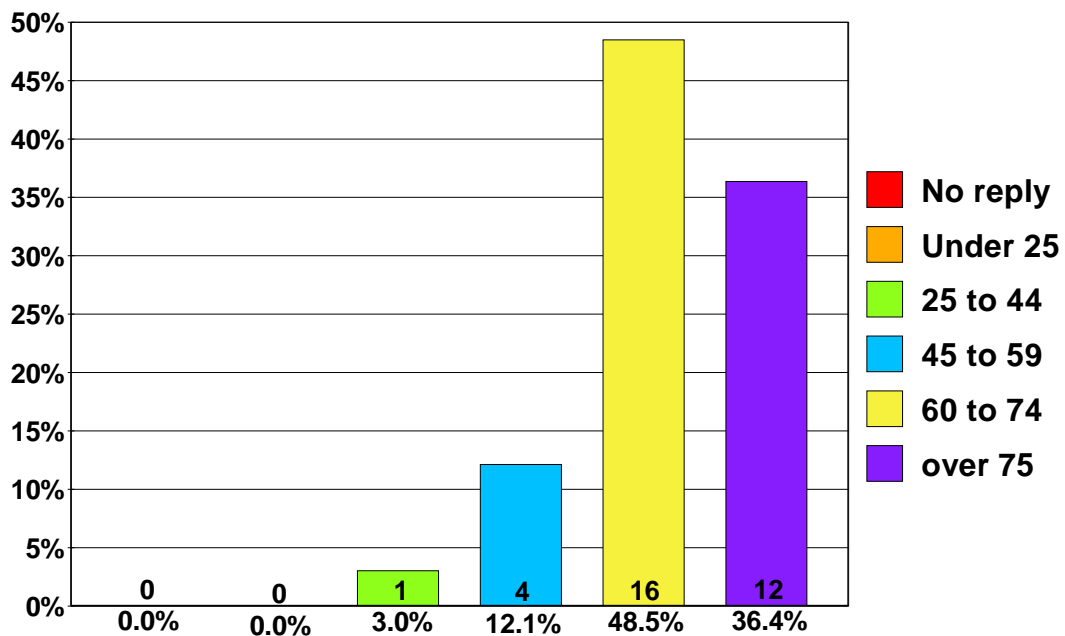
What is your greatest fear or concern about your condition deteriorating?

- I cannot worry too much - what comes, comes. I am also looked after very well by my heart nurse and specialists.
- I do not think about it. I have good service from my GP, Cardiac Nurses - well looked after.
- I'm into positive thinking.
- I am learning to live with it one day at a time.
- Since by-pass and pacemaker my condition has improved.
- I put it at the back of my mind.
- None.
- My main diagnosis is multiple myeloma, which is at present in remission. The heart condition is a result of chemotherapy and not a major concern. It is too early to consider use of hospice services.
- Increased lack of mobility and dulling of mental powers.
- That I may be completely bed ridden.
- Living on my own.
- Being alone.
- Not being looked after.
- Mental deterioration. Ability to go out.
- I will become totally dependant with my other condition (Inclusion Body Myositis) as well as heart failure and will be unable to stay at home.
- The biggest fear is not being able to manage on my own anymore, and having to move from my home. Also, the fact that I am under Papworth Hospital in Cambridge means that if I deteriorate I would be miles from my family if I was admitted.
- Almost totally reliant on my wife.
- I do not think I could deteriorate anymore because I have an idea of living to mark my centenary.

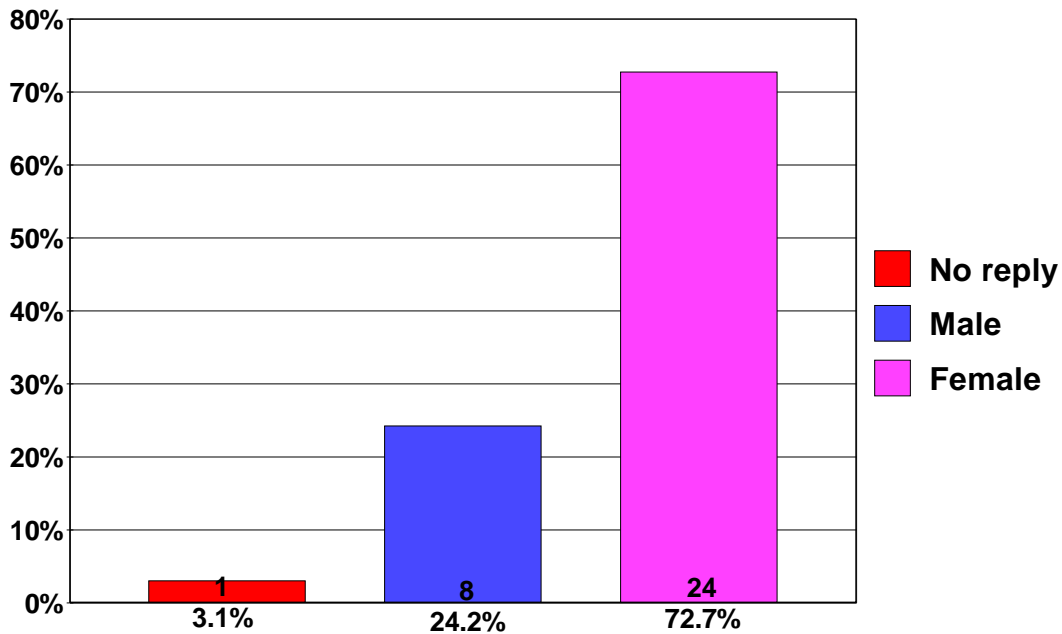
- That I put more pressure on 'my wife and daughter' as I suffer from other complaints other than heart failure (Prostrate Cancer / Parkinsons).
- Being a burden to my wife and family.
- That I may lose my independence.
- That I will lose my independence and be put in a home.
- Going into hospital.
- Any pain, losing control of body functions.
- Having survived RAF flying service during and after WW2 and having been close to death, my only fear is pain during the final days and not completing those social/gardening tasks.
- My death.
- Death. Losing the will to live. Not having enough reasons to keep going (or fighting on).
- Having Heart Failure.
- Dying.

3b. Findings – Carer Questionnaire

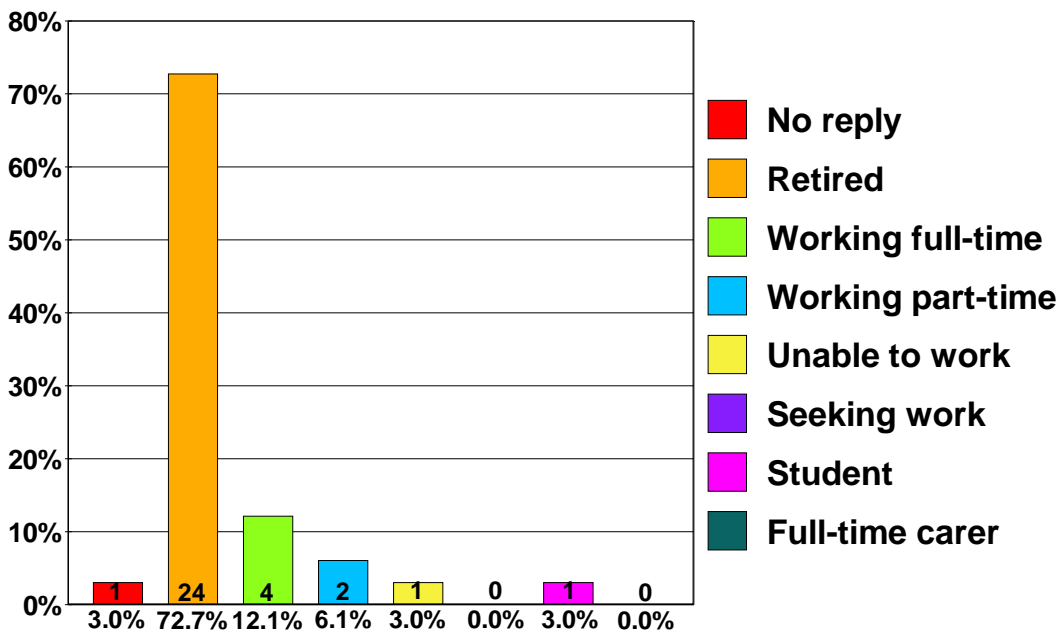
1. Age group



2. Are you male or female?



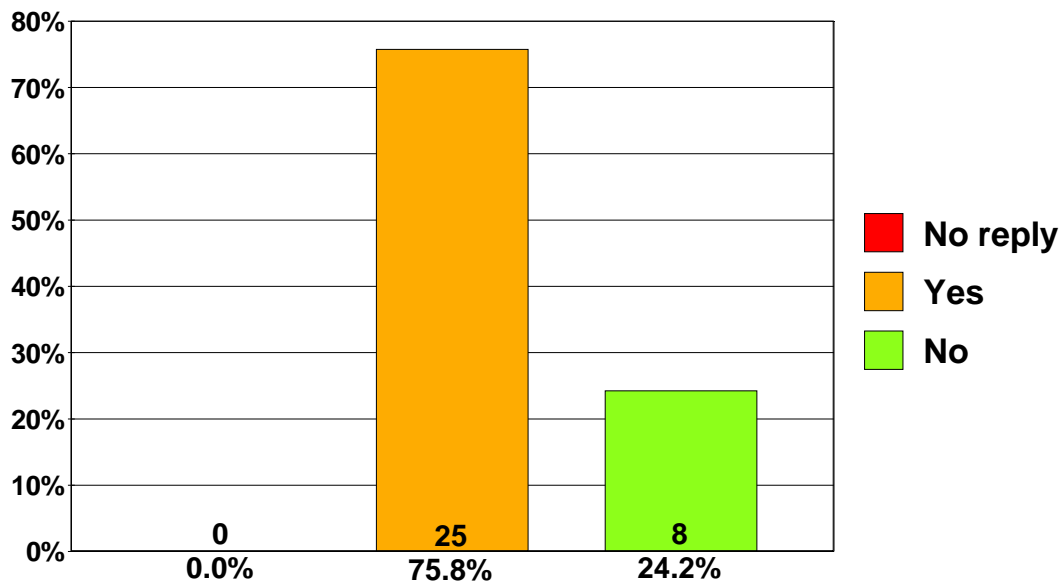
3. Which best describes you?



Other, please state

- Wife looking after husband.

4. Do you feel that the life of the person you care for will be limited due to heart failure?

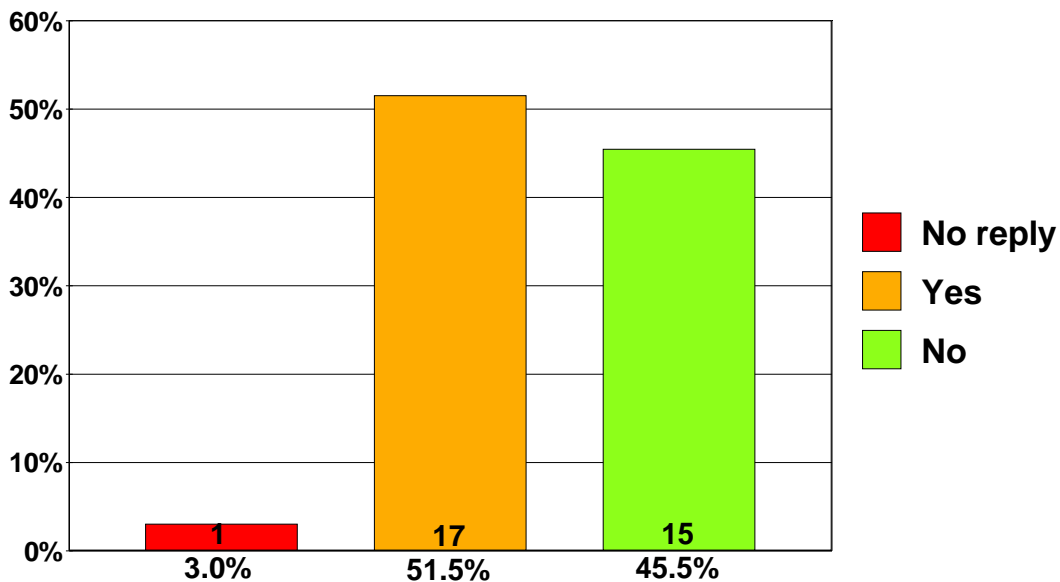


If you feel that the life of the person you care for will be limited due to heart failure, how does that affect you now?

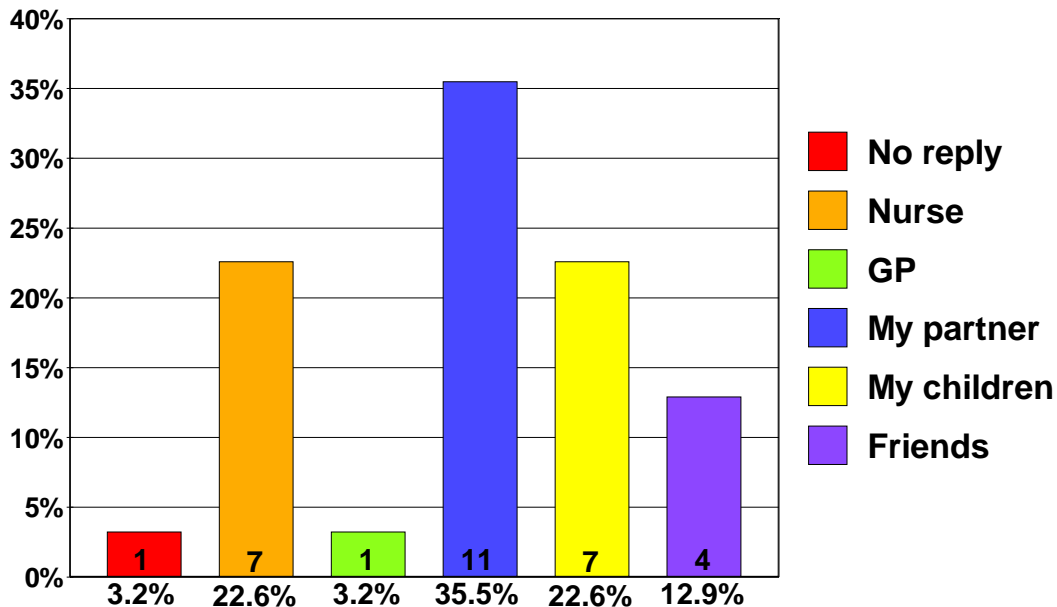
- Doesn't.
- I think positive and take each day as it comes
- Currently, my dad is active and well, so it only affects me now in the fact that I'm worried about he could be in the future.
- When out of the house must use a wheelchair.
- We don't go away for holidays or out much.
- We are very grateful for the care of the Cardiac Nurse, she is very supportive. We have good days and not such good days, so we take each day as it comes.
- I have to do almost everything, sorting tablets, washing, making bed, gardening, driving, and washing-up after meals. Occasionally cleaning up after dia upsets.
- Can't go for walks like we always have done. He can't do decorating around the house like he used to. Lost my odd job man.
- Constantly worrying that his life is shortened because of this. He has since had a heart attack and apart from being diabetic and is very immobile, it is a constant worry.
- The number of activities we do together is now limited, due to my husbands limited mobility, as very breathless on exertion and unable to make plans as he has good and bad days.
- Husband is house-bound and has inclusion body myositis with greatly reduced mobility, as well as severe heart failure and requires constant attention
- Upset at his limitations.
- Constantly on my mind. The listening for him when I wake up in the morning. Being careful not to moan at him and feeling dreadful when I do! Living every day as best we can but with this dreadful foreboding feeling there all the time.

- It contributes to the depression I suffer with. Restricts some activities.
- Restricted and reliant on children to take my husband out.
- Concerned about what will happen. The future, and seeing my husband deteriorate.
- Very concerned.
- It makes me alert and very watchful.
- My husband is unable to lead a normal life. He is exhausted after walking more than 5 yards or even walking for a few minutes. He is very depressed, has difficulty sleeping and is generally in a very poor state.
- I have accepted the inevitable, but if it could be reversed that would be good.
- We are both over ninety and of course whilst I hate the thought of being on my own, we do accept that there is not that long for either of us.
- Shock at first, now I'm very frightened. Sad also to see my very active husband go down hill so very fast and very hard work looking after him.

5. Have you discussed end of life issues with any health professional or family members?



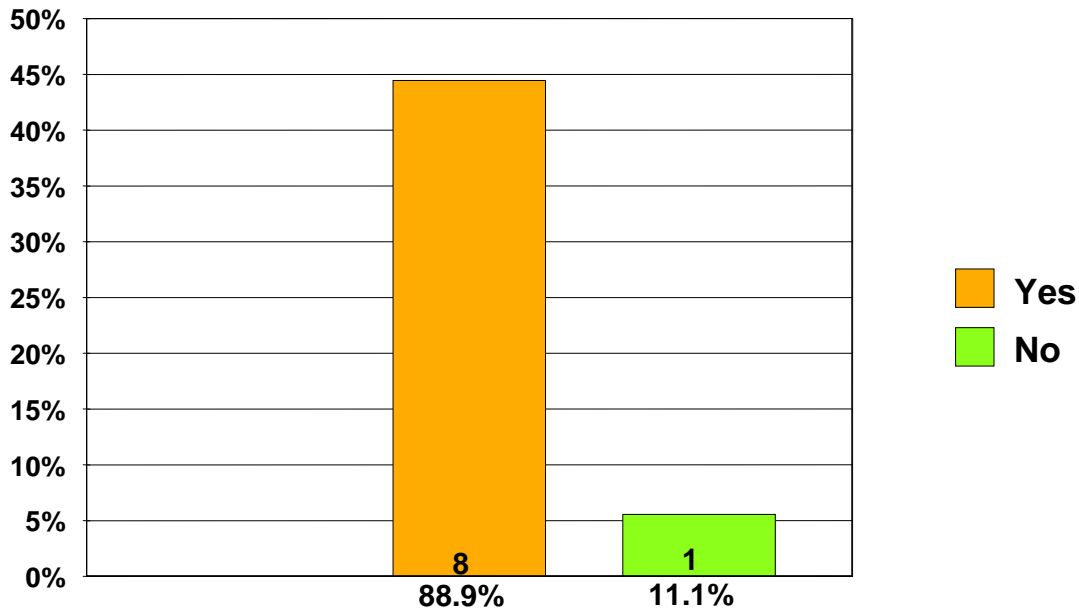
6. If answered yes to Q5, who with?



If you discussed end of life issues with any health care professionals or family members, how did it make you feel?

- Vastly relieved knowing my partner should have no real problems with which to deal.
- It was good to know, but it also worried me greatly.
- It is something that has to be done.
- Easier.
- Better for finally having spoken out loud what I had been thinking.
- Better knowing that if anything happens to us the other would be looked after.
- Settled knowing that everyone knows our wishes.
- Very sad.
- Sad, understanding and helpless.
- 2 patients said 'sad'.
- Upset.
- Also spoke to Hospice Doctor. Felt no better. We can't change things. But it really brought it home to me when the hospice doctor actually told it how it is. Hospitals never really talk to you like that.

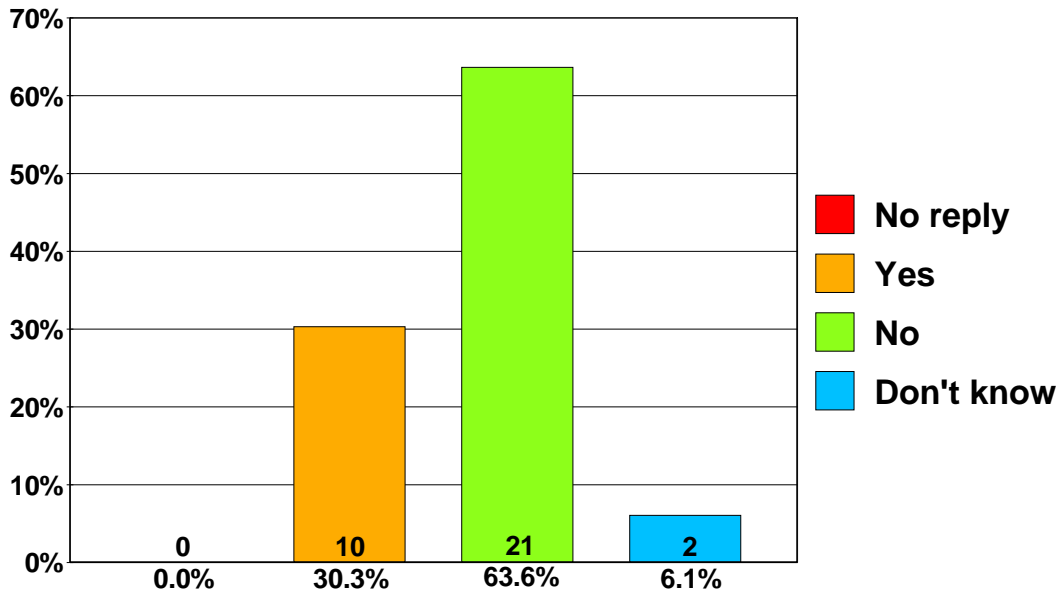
7. If you discussed end of life issues with a nurse or your GP, do you think it was done at an appropriate time?



If you discussed end of life issues with a nurse or your GP, do you think it was done at an appropriate time?

- It was during routine appointment.
- Possibly.

8. Has the person you care for been referred to the hospice team?



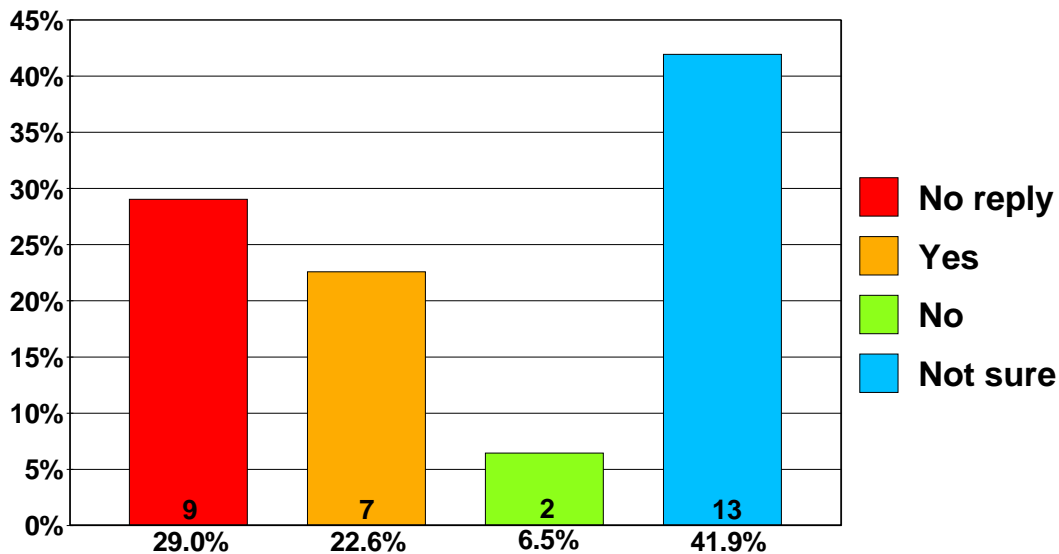
If the person you care for has been referred to the hospice team, what services have you both found the most helpful?

- Home visit.
- 'Caring with Confidence' - I found most helpful and informative. The hospice staff are wonderful and I can't praise them enough.
- The Respite Care the hospice nurse and cardiac nurse offered me as a carer who needed a regular break. This was a lifesaver for me and I was so grateful for it.
- Day Centre, Carer's Days and Respite Breaks.
- Breathlessness Group.
- The hospice arranged for me to get the correct DLA for my husband, they completed all forms etc.
- All.
- Physiotherapy classes.
- Day hospital.
- All services at the hospice have been more than 100% wonderful - cannot fault anything.

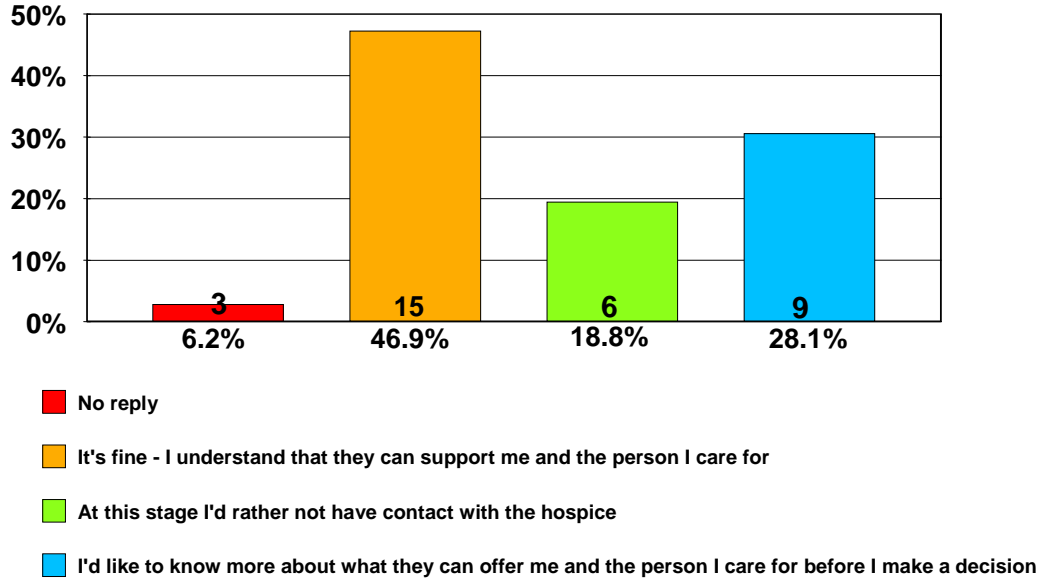
If the person you care for has been referred to the hospice team, what services have you both found the least helpful?

- The arrogance of a consultant who thought he knew better than me (the carer who was with the patient 24/7) and refused to run off the ICD at the time I suggested, thus causing unnecessary pain and stimulations and shocking near time of death.
- GP.
- Telephone.
- 3 carers said 'None'.

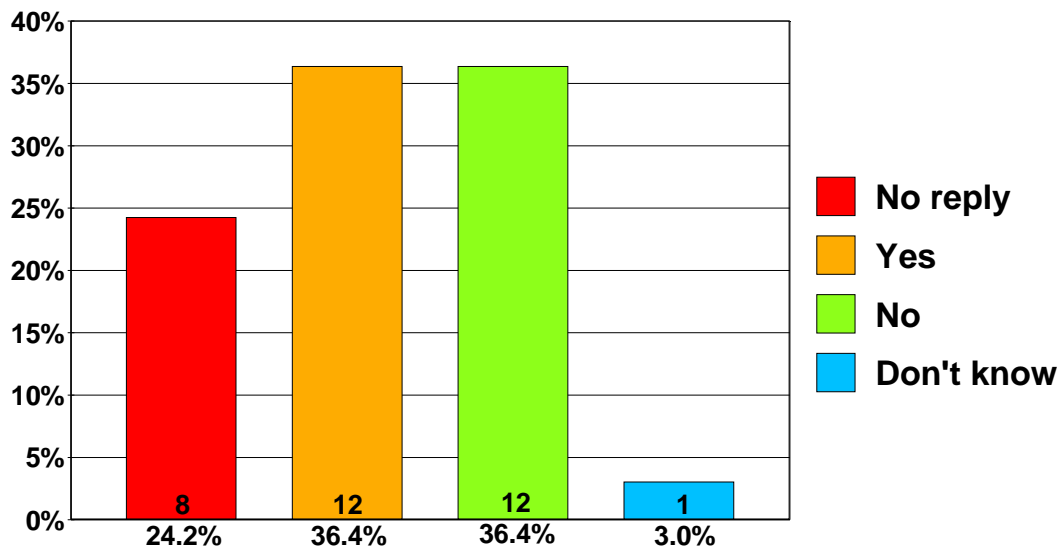
9. If the person you care for has not been referred to the hospice, would you like support from the hospice team in the future?



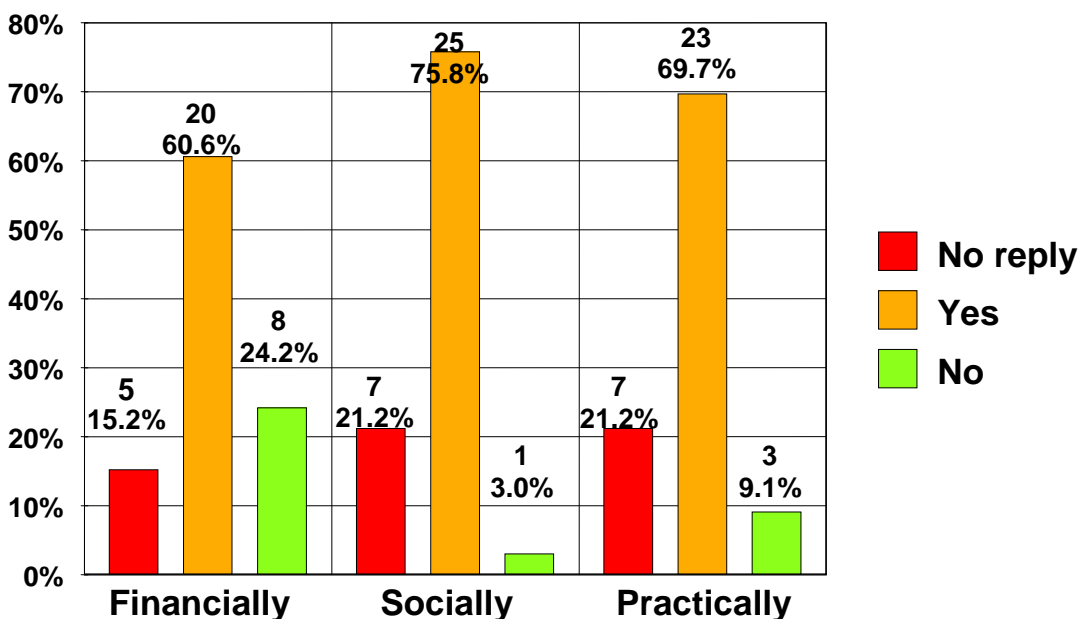
10. Which of these statements best describes your feelings about receiving services through the hospice?



11. Do you know if the person you care for has thought about making a 'Lasting Power of Attorney' or Advanced Directive' in order to help plan for the future?



12. Do you feel adequately supported?



13. What is your greatest fear or concern about the deterioration in condition of the person you care for?

- None, we have a good relationship with our GP, friends and family.
- At her age I view this not only relative to heart failure but in general. I don't want her to have pain and I would hope she could maintain a reasonable quality of life.
- My husband's problem is well controlled and presents no immediate problems. The fact that he is in remission from Myeloma is pleasing, but this is more likely to cause us to seek help in the future.
- Not knowing what to do or who to contact.
- That I don't think I will be able to cope although I am sure I will, having done so with both my parents, my mother who died nine years ago and my father nearly three years ago. A person up there seems to help.
- That he may have an attack of breathlessness and there is not a thing I can do to help, other than call an emergency ambulance if he is very bad. He has attended the breathlessness management program at the hospice and he has found this helps to keep him more calm during an attack (possibly shortening the attack).
- That my husband may not be able to cope mentally.
- That the condition will deteriorate to a level where it cannot be managed at home and the indignity of not being able to do anything for himself. Poor quality of life makes him very depressed.
- Not being able to do anything for themselves.
- Having time to care for them as I work full time.
- I will lose my soul mate, the love of my life.
- I wouldn't want anyone else to do what I do. He is a very proud man. He is fully compos-mentis and has his pride. I worry that I fall ill and couldn't care for him as I do now.
- That I will not always be able to look after him, due to my age.
- Due to my own health problems, the difficulties of continuing to care for himself at home.

- I am worried not only for myself but also my children when my husband deteriorates more. Even now it is upsetting to watch him struggle to cope with everyday activities like washing, dressing etc - he was a strong independent man.
- My greatest fear is seeing my dad deteriorate and become very poorly. He doesn't want to have to be looked after and he would rather be left alone to die if he becomes incapable and I'm not sure how to cope with that. I will want to do all I can to help him but he won't want me to.
- Not able to look after my husband, if my own health changes. Also fear the unknown, and fear I won't be able to cope.
- That I won't be able to cope and I will not be well and be able to be here for him.
- My greatest fears are that my husband will be in pain for a long period as he is now. Also have a terrible fear that he will have a heart attack at home and because he has a defib in, that it will be very frightening to anyone who is here, most particularly my 6 year old grandson who is here most of the time.
- That there may be something I could do that would help but I haven't thought of it in time. That he is alone during the day time as I work. That he is frightened ever.
- My greatest fear is coming home and finding that my husband has died and then feeling I'm on my own. I feel sadness seeing him looking so ill and I can't do anything to help him, apart from looking after him the best way I can.

4. Discussion

This section was completed by Jane Thackwray, Head of Community Cardiac Services.

The return rate for responses was good and was typically reflective of the heart failure population with regard to age. The current problems/symptoms being experienced by patients were reflective of large scale research projects. Most patients were aware that they had a life limiting disease, however only 48.8% had discussed end of life issues. For those that had discussed end of life, this was mainly with family members and only 24% had had discussions with a health professional.

There seemed to be an awareness of the hospice and the services it could provide, however it was surprising that large numbers of responders did not want information regarding Lasting Power of Attorney and Advance Directives. Whether this is due to a lack of knowledge and understanding of the subjects or whether this reflects true feelings is difficult to interpret.

Patients and carers felt well supported, disclosing typically reported fears of being alone and losing independence, but also reported positive responses of wanting to live for today.

The carers were typically in the over 60 age bracket, mainly female and mostly retired.

5. Recommendations and Conclusion

The findings of this survey were used to determine themes for 3 focus groups held during November 2009 for patients with Heart Failure and their carers. The responses from the survey were upheld by the Focus groups and the action plan below is in response to both engagements. The findings from the focus groups are shown in Appendix 3.

Action Plan		Title: Heart Failure Service Questionnaire				
Ref Number:	PES/038/09	Date Action plan agreed and confirmed by project lead: 25 / 01 / 10				
Date the Patient Experience Group Chair was Notified of the Action Plan: / /						
No.	Recommendation for improvement	Action to be taken	Evidence of action	Responsible person	Date action(s) to be completed by	Comments
1	Written information regarding Hospice services	Review existing literature and create a leaflet for patients and carers prior to hospice referral. For those not requiring input from the Hospice consider producing a generic leaflet with disease specific insert for Heart Failure.	Leaflet ratification and distribution	Jane Thackwray / Keith Duffy	30 th April 2010	
2	Patient-Held Record book to include space to add names of health professionals involved in the care and their contact details	Record book currently being reviewed	Ratification of booklet	Sue Dilworth	30 th April 2010	
3	Clear Crisis Management Plans in patient records and in the Patient-Held Record book	a) Discuss at team meeting. b) Section of patient records and patient book to be completed.	Meeting minutes Ratification of booklet	Jane Thackwray / Sue Dilworth	1 st Feb 2010 30 th April 2010	

No.	Recommendation for improvement	Action to be taken	Evidence of action	Responsible person	Date action(s) to be completed by	Comments
4	Improving knowledge of health professionals in delivering palliative care in heart failure	a) Process mapping event planned for March 2010 b) Offer to provide education at hospital sites, GP education sessions	Outcomes from event to be determined Advertise education to organisers of events	Keith Duffy / Jane Thackwray	30 th April 2010	

Appendix 1 Copy of Blank Patient Questionnaire

Patient Questionnaire

We don't need your name and please be assured that your answers will remain anonymous and confidential.

Age group: Under 25 25 to 44 45 to 59 60 to 74 over 75

Male female

Which best describes you?

Retired Working Full-time Working Part-time

Unable to work Seeking work Student

Other, please state:

How long ago were you diagnosed with heart failure?

What are your current problems? Please tick all that apply:

Breathlessness Chest pain Cough
Swollen ankles Fatigue Poor appetite
Unable to sleep Anxiety Other, please state:

Do you feel your life will be limited due to heart failure? Yes No

If yes, how does that affect you now?

Have you discussed end of life issues with any health care professionals or family members?

Yes No

If yes who with? Nurse G.P. My partner My children
Friends

How did it make you feel?

If you discussed this with a nurse or your GP, do you think it was done at an appropriate time? Yes No

If no, please explain:

Have you been referred to the hospice team? Yes No
If yes, what services have you found the most helpful?

What services have you found the least helpful?

If you have not been referred to the hospice would you like support from the hospice team in the future? Yes No Not sure

Which of these statements best describes your feelings about receiving services through the hospice? (tick one)

It's fine – I understand that they can support me and my family

At this stage I'd rather not have contact with the hospice

I'd like to know more about what they can offer before I make a decision

Would you like information about making a Lasting Power of Attorney or Advance Directive, in order to help to plan for the future?
Yes No I've already made one

Do you feel adequately supported:

Financially Yes No

Socially Yes No

Practically Yes No

What is your greatest fear or concern about your condition deteriorating?

Thank you for your time. Please return in the envelope provided by 31st October 2009

Page 2 of 2

Appendix 2 Copy of Blank Carer Questionnaire

Carer Questionnaire

We don't need your name and please be assured that your answers will remain anonymous and confidential.

Age group: Under 25 25 to 44 45 to 59 60 to 74 over 75

Male female

Which best describes you?

Retired Working Full-time Working Part-time Unable to work
Seeking work Student Full-time carer Other, please state:

Do you feel that the life of the person you care for will be limited due to heart failure? Yes No

If yes, how does that affect you now?

Have you discussed end of life issues with any health care professionals or family members?

Yes No

If yes who with? Nurse G.P. My partner My children

Friends

How did it make you feel?

If you discussed this with a nurse or your GP, do you think it was done at an appropriate time? Yes No

If no, please explain:

Has the person you care for been referred to the hospice team?

Yes No Don't know

If yes, what services have you both found the most helpful?

What services have you both found the least helpful?

Page 1 of 2

If the person you care for has not been referred to the hospice would you like support from the hospice team in the future? Yes No Not sure

Which of these statements best describes your feelings about receiving services through the hospice? (tick one)

It's fine – I understand that they can support me and the person I care for

At this stage I'd rather not have contact with the hospice

I'd like to know more about what they can offer me and the person I care for before I make a decision

Do you know if the person you care for has thought about making a Lasting Power of Attorney or Advance Directive in order to help to plan for the future?

Yes No Don't know

Do you feel adequately supported:

Financially Yes No

Socially Yes No

Practically Yes No

What is your greatest fear or concern about the deterioration in condition of the person you care for?

*Thank you for your time. Please return in the envelope provided by 31st October
2009*

Page 2 of 2

Appendix 3 Findings from Heart Failure Focus Groups

Heart Failure Focus Groups

Ashford 24.11.09 – 3 patients, 3 carers

Q: How can we help you to think about and plan for the future / end of life?

- Community Services/Hospice to discuss these issues with hospital
- Planning and having the best possible active life
- Emergency treatment affect on patient and carer – out of hours issue
- Not sure its helpful (if the person you care for is reluctant to talk about it)
- Who do we turn to, to get advice?
- Different for carers and the patient
- Need information – legal issues
 - Timing
 - Making GP aware – procedures
 - Preferences – choice
- Opportunity to talk but separately - carer/patient on their own

Q: When and how do you want information about hospice services?

- People have pre-conceived ideas about hospice care
- Information about who makes the decision on hospice vs. hospital – the process
- Who refers to the hospice? – can self-refer by asking the GP or nurse, do patients know this?
- Hospice care is not linked to any particular condition – it could be one or several. We need to tell patients/carers this.

Q: What type of support would help carers?

- Contact person – make more use of voluntary organisation
- Carers who work/care have no time to go to groups or get support
- Practical advice/information – in a range of formats e.g. DVDs, website and leaflets
- General information on carers assessment
- Preventative care
- Information on support for younger people e.g. grandchildren

Q: What do you think makes a good heart failure service?

- Change the name of the services
- Freedom to contact the heart failure nurse by mobile – out of hours not available, some people can contact Community Matrons
- Balance – choice of how much care/attention (flexible as can feel there is too much care)
- Individual services – you need to ask people what they want
- Feedback of tests – better links between hospital and nurses

Q: Other issues raised (when staff left the group)

- The age you are when diagnosed affects how you see it
- Value the support that heart failure nurses provide

- More information – an updated diagnosis/or assessment – is it as ‘bad’ now as it was when diagnosed?
- People very confused about what the term ‘heart failure’ means
- Has the prognosis changed? – am I really still a ‘heart failure’ patient
- Can they change the name?
- Don’t Google ‘heart failure’ – it’ll scare you

Canterbury 25.11.09 – 3 patients, 2 carers

Q: How can we help you to think about and plan for the future / end of life?

- Worries about financial planning – need information on where to get advice
- Advice on fitness to travel (not sure where to get advice) – British Heart Foundation can advise and so can your heart failure nurse
- Being clearer about the scope of the support we can provide – its not just healthcare
- Difficulties in getting needs recognised i.e. for benefits and support – ignorance amongst non-health and other health agencies about what heart failure is – so we need to address this

Q: What information do you need about hospice services? And when?

- Want more information on how to get referred, by whom, when and who funds it
- What complementary therapies are available via the hospice? – are they free?
- Educating cardiologists and GPs about what the hospice can offer and when – its not just at the end of life

Q: What support can we give to carers? Family and friends?

- Out of hours support – hospice nurse on call
- Support at the very end of the life of the person they care for
- Decisions patient makes about where to die/be may not be carers choice or put extra strain on them
- Good pain management and explain to carers what’s needed
- Out of hours forms should be on the system
- Information on benefits/financial support for carers and on equipment and social care

Q: What do you think makes a good heart failure service?

- Available more than 9am-5pm
- Single point of contact
- Good on-call out of hours system
- Support to navigate the ‘system’ and co-ordinate support during times of stress and illness
- Cardio ‘technicians’ and consultants with empathy
- We need to learn from the Scottish study of heart failure and palliative care
- Community nurses understanding end of life process

Q: Other issues raised (when staff left the group)

- Dealing with uncertainty of life span – affects quality of life
- Information is good but needs to be less ‘in one go’ and less ad hoc (respect the amount people want)

- Co-ordination is poor - need heart failure service to have the power to co-ordinate
- Heart failure nurses listen, others don't so much
- Importance of relationships developed with heart failure nurses – this is so valuable
- Heart failure service is the 'poor relation'

Margate 27.11.09 – 2 patients and 4 carers

Q: How can we help you to think about and plan for the future / end of life?

- Recognise that it's different for patients with an ICD at the end of life. Not all doctors are aware it needs to be switched off, but the carer/family are which causes extra distress
- Listen to people's wishes
- Need more awareness of choice / control – e.g. hospice can provide information on Lasting Power of Attorney and Advance Directives
- Better link between HFS / hospice and hospital regarding decisions / preferences of patient regarding end of life – a joined up approach
- End of life discussion to be done by the healthcare person that knows the patient best (and their condition / treatment); who has the relevant information and whom the patient and carer knows and trusts. The 'wrong' person raising the issue causes distress.
- Family and patients to have a chance to discuss end of life issues / the future separately from the person they care for / their carer
- Each person is different about when they want to discuss end of life issues
- For patients with an ICD it would be helpful to discuss this when the ICD is fitted
- The wording of end of life question in the carers survey caused surprise/shock for two of the carers who had not thought about end of life issues

Q: What information do you need about hospice services? And when?

- More information for carers / family about services available, e.g., respite, support to help parents tell young children, groups for carers, Caring with Confidence course (and how to get on it)
- People generally think hospices are just about dying – we need to dispel this myth
- Information on helping symptom control and improving quality of life

Q: What support can we give to carers? Family and friends?

- Access to a named person (nurse) for the family but in particular for the main carer to have, and to pass on to other family members as appropriate
- Out of hours support – someone at the end of the phone

Q: What do you think makes a good heart failure service?

- Continuity of nurses – the same one or a regular one really helps. Continuity is important at the start of life (named midwife) so it should be at the end of life.
- Regular visits from the HF nurse give continuity of care and enables good follow-up of issues.
- Linking patients / carers to information on additional types of help, e.g. financial, benefits

Q: Other issues raised (when staff left the group)

- “I’d like to thank Anita – she put my mind at rest”
- Do doctors in hospitals have the power to over-rule the HF nurse / hospice and previous decisions made and agreed?
- “every heart failure nurse we’ve had has been faultless”