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## Communication in the Palliative Care Team

### Komunikacja w zespole opieki paliatywnej

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## A Model of Palliative Care Communication

Figure 1 sets out a model of communication in palliative care. It identifies three major issues to explore:

1. Palliative care is nested within wider health and social care services, including general community services available for everyone; services concerned with end-of-life care for people with long-term conditions or disability or experiencing increasing frailty in old age; and specialist treatment services for people with serious illnesses. Communication among these different services must be explored. The palliative care team is also part of a wider network of colleagues working in those services and beyond. They have to establish links within that network and communicate across those links.

2. The patient, their families and the community in which they live and in which the service is situated is important in communication. Palliative care patients and their families follow a pathway from full health and a good state of social well-being, through a series of transitions towards the death of the patient; and for the family the pathway continues beyond the patient's death into bereavement. Services have to communicate with and about the patient and family as they progress through those transitions.

3. The palliative care team usually consists of a core team of professionals actively and continuously engaged with the patient and their family and a periphery of professionals occasionally working with the patient. They have to communicate with each other across professional barriers and sometimes across service boundaries.

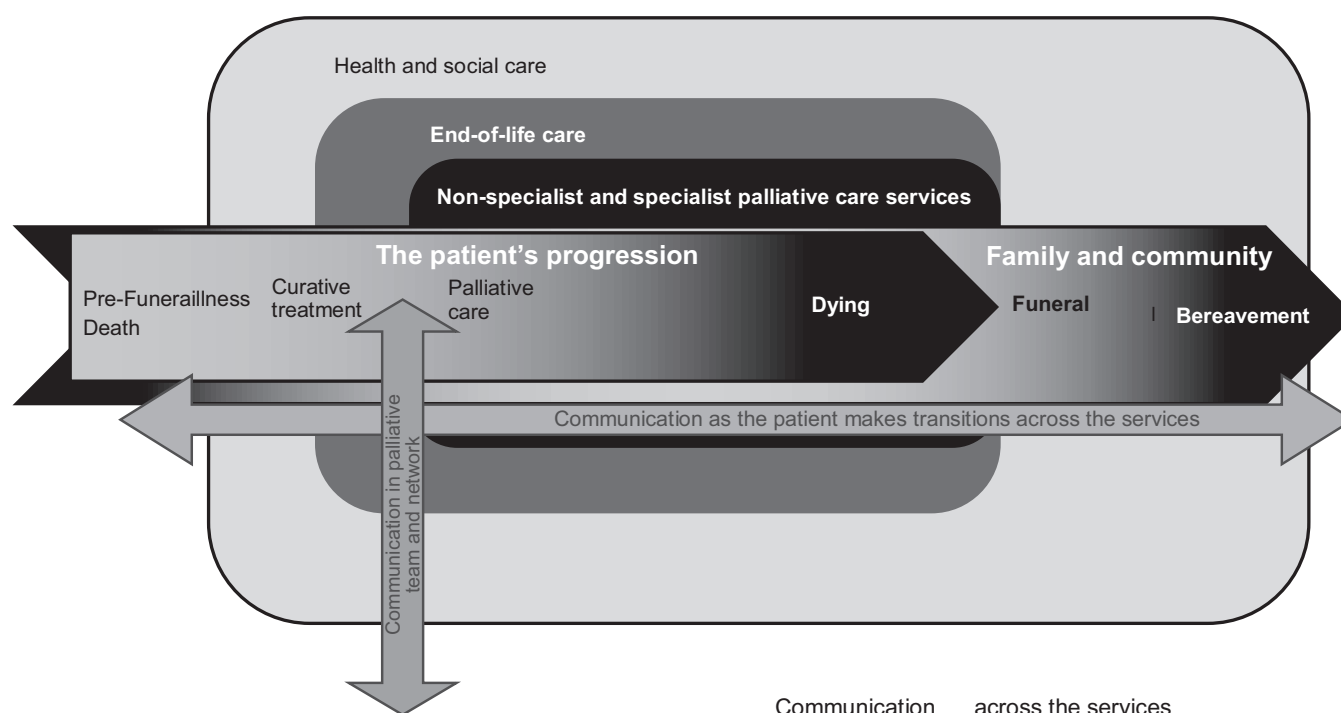
This paper considers, first, why communication in end-of-life and palliative care presents problems for all professionals, then looks at the problems arising around each of these three issues. Finally, it explores ways of responding to communication issues in palliative care teams.

## Why is Communication in End-of-Life and Palliative Care Difficult?

Why is communication not only important but also difficult in providing palliative care services?

One reason is that although communication is something that everyone does every day, people are often not accustomed to raising, discussing and resolving issues about serious illness, death, dying, and bereavement and their personal consequences [27]. Professionals, patients and people in patients' families and communities need help to communicate with each other in end-of-life and palliative care because these are such difficult issues to discuss and they are often avoided in everyday life, so people do not know how to broach them. Important but difficult areas include:

- breaking 'bad news', that is, communicating information that seriously and adversely affects patients' views of their future;
- discussing prognosis, communicating risk and discussing recurrence of disease, when long-term and advanced disease is highly variable in its impact;
- achieving shared decisions among professionals, patients, family caregivers and others in the patient's social network;



**Fig. 1.** Model of communication in a patient's pathway through end-of-life and palliative care

**Ryc. 1.** Model komunikacji w opiece paliatywnej

- dealing with difficult emotions;
- communicating with relatives and in family meetings [17].

Another reason is that, by definition, palliative care is a multiprofessional service, incorporating medical, nursing, psychological, social and spiritual care. Few health and social care services employ this range and diversity of colleagues from different professional disciplines, and there are many barriers to effective communication among them [17].

A third reason is that communication is a complex process involving: people who communicate; people who receive and react to a communication; the message that is communicated; different forms of communication, for example spoken communication and the linguistic and paralinguistic aspects of speech, body language and written communication; different objectives of communication; intentional and unintentional implications that the message carries; the cultural, legal, social and institutional contexts within which the communication takes place.

Professional communication takes place not only in clinical settings such as hospital wards and interviews between patients and professionals but also in professional meetings, such as case conferences and clinical reviews, and through records systems, letters and reports [11, 53].

When applied to the difficult issues of palliative care, across the range of professionals and others involved in caring for dying and bereaved

people, the range and complexity of these factors extends the demands on communication beyond everyday skills into a specialised set of skills. Street and Blackford [46] suggested that concentrating on communication with patients has led to a lack of attention being paid to improving communication in interprofessional teams.

Focusing on communication barriers that come from patients' and families' experiences of involvement in end-of-life care, Sheldon [44] identifies the difficult emotional reactions often experienced or expressed by patients and families, which demand skilled communication in end-of-life and palliative care:

- adverse reactions when 'bad news' is communicated;
- the protective carer, who wants patients to be protected from knowledge of or responsibility for their condition and progress;
- anger that arises from a sense of powerlessness over the progression of the illness;
- denial of the illness or its progression, which prevents people from making rational decisions about their care and treatment;
- depression and despair, which may reduce the patient's capability to make decisions or participate in helpful relationships with others;
- fear about death or the impact of possible unpleasant symptoms such as pain and breathlessness;
- uncertainty;
- asking for assisted suicide or euthanasia.

Another difficulty may be how messages are conveyed. This may take place through interpersonal spoken and non-verbal communication; written communication, either directly, or through such means as care records; and communication through electronic devices such as telephones and possibly more complex equipment offered in telemedicine and telecare [36]. Technology sometimes feels intrusive or uncomfortable to people, and discomfort inhibits good communication.

An important concern in communication is confidentiality of personal information. Increasingly, human rights concerns and professional concerns have arisen because patients, and sometimes family members, have rights to have access to medical records, while professionals continue to have the responsibility of maintaining the privacy patient's information. This raises many practical and ethical issues for professionals and for agencies providing services. Palliative care raises additional difficulties because it specializes in dying patients; deaths may raise questions about access to and use of information after the patient is able to give consent and after death [37].

## **Palliative Care as Part of Wider Services**

Palliative care is nested within end-of-life care, curative health services and everyday social care. Palliative care services are provided in the following settings.

Community health and social care services are the backbone of everyday care. Most people receiving palliative care have received occasional health-care treatment throughout their lives and this continues. Older and disabled people are often also receiving social care services to support independent living in the community.

In general or geriatric hospitals, patients receiving in-patient, day-patient or out-patient care for a disease such as cancer, renal failure or chronic obstructive pulmonary disease reach a point at which good quality supportive care becomes more important than treatment or the two elements are re-balanced in the whole treatment regime. Many hospitals have a specialist palliative care team providing consultation to ward staff on this phase of care and sometimes have specialist palliative care beds or day centres to which patients can be moved.

Hospices may provide a building in which specialist palliative in-patient care or day care can be provided, or may primarily be a community home care service, supporting community health and social care services where the specialised approach of palliative care is required for particular patients.

Sometimes, in-patient and day-patient and community provision is combined in one organisation; elsewhere only some elements of this provision may be available.

Patients therefore need to be referred and transferred effectively between these different elements of services, and information needs to be communicated that enables each element of the service to respond appropriately.

Increasingly, health and social care policy recognizes the need for broader end-of-life care provision in everyday services for people in old age or who suffer from long-term conditions or disability. End-of-life care within broader health and social care provision helps people to recognise the reality that their existing conditions or disability and increasing frailty in old age will eventually lead towards death, and helps them to prepare for this. Preparation includes expressing their preferences about services and treatments. This is called advance or anticipatory care planning, and includes authorizing others to make decisions for them about treatment if they lose consciousness or in other ways lose the capacity to consent to treatment. Advance directives clearly set out circumstances in which they do not wish to receive treatments, such as cardiopulmonary resuscitation and treatment for infections when they are approaching death. More broadly, they may wish to specify in advance important aspects of their care provision, such as diet or religious observance [35].

In cases when patients have long periods of care and treatment for disease before they are referred to palliative care services, their experience of these services provides a context for palliative care. They may have experienced debilitating and unpleasant treatments and good or bad service that will colour their expectations of palliative care. Treatment may continue alongside palliative care for conditions other than the illness that has led to their receiving palliative care. Patients therefore engage with a range of services in their pathway towards death and communication with other services outside palliative care is frequent and important in achieving suitable care for patients in their own home [54] and in hospital. Randhawa et al. [39] show that good communication using interpreters is important in providing services that take account of the culture and ethnicity of patients and their families.

Moreover, since the 1970s, public policy across the world has focused on the need for integration of services, particularly where people suffer from long-term conditions [13, 36]. To develop and manage services in a locality requires attention to a number of different elements of communication and organisational consensus-building. In a Cana-

dian study Morin et al. [24] identify six elements of a network that need to be constantly held in play:

- territorial partnership, that is, ensuring that stakeholders in the relevant locality are involved;
- intra-organisational and inter-organisational cooperation, because support is needed both within an organisation providing end-of-life and palliative services and with organisations not directly engaged in the provision of these services;
- interprofessional collaboration, so that professional attitudes are aligned;
- community contribution from people and organisations that can provide financial and political support;
- familial contributions from family caregivers, who always make the main contribution of time and effort in any caring process, which means that professional services need to be interwoven with family caregiving, involving sometimes delicate communication;
- patient involvement, not just in consenting to engagement with end-of-life and palliative care but in adjusting the services constantly to their rapidly changing needs.

Attitudinal barriers between different organisations were identified in an American study by Lau et al's [20] of relationships among hospices, family caregivers in their own homes and nursing care homes. These included a feeling that people 'owned' the setting in which care was given (their own home, the care home or the hospice) and therefore should control what went on there; a feeling that family relationship, specialist expertise or experience caring for the patient gave better expertise in understanding the patient's needs; distrust towards specialist providers; and the interplay of powerful emotions about death and dying. Differences in service priorities meant that policies were not aligned and some settings were not ready to provide care to particular patients when others thought this was necessary. The reasons for services refusing to provide care when other services thought it was required included poor communication, because the full implications of the patient's situation was not communicated in a way that enabled another service to see what they could contribute; disagreement about the need for palliative care or discussion about end-of-life care options; or simply work overload.

## Patient and Family Transitions

Each transition between these services can be important for patients, and often there is a fairly predictable pathway from everyday health and so-

cial care, which may include end-of-life care, to treatment for serious illness, a referral to palliative care and finally, after the patient's death, their family's transition to bereavement care. The predictability of this pathway can help us to plan to overcome communication and coordination difficulties.

The following main areas often raise difficult communication issues.

Raising awareness, as people move towards old age, of the need to plan for future care needs, including end-of-life care. Evidence suggests that this increases patients' satisfaction with services and the likelihood that patients' plans will be achieved [40, 42]. It is important to develop skills among non-specialist health and social care staff in identifying when people are ready to take part in these discussions and to develop staff members' confidence in discussing outcomes that patients or practitioners may fear or avoid [41, 45].

The transition between curative treatment and palliative care services, when patients are told the 'bad news' that their condition is no longer treatable and are transferred to palliative care. In particular, patients often do not understand the significance of this shift in service [19]. One of the important aspects of this transition is telling patients and families the truth about the 'bad news' that the patient has reached the terminal stage of their illness. This is a basic requirement of providing palliative care in a transparent way, but in particular cases there may be cultural and personal differences about whether this is considered desirable [14]. Team functioning is also affected by the paradigm shift from curative to palliative care, particularly where philosophical differences and a lack of respect for alternative professional disciplines affect a team [49]. This shows how important attention to developing and maintaining team functioning can be to providing effective care and treatment.

The transition from the patient's care to bereavement care for the family. Death is an important boundary to medical palliative care, but most palliative care services also provide bereavement care, usually as part of social work or counselling services. Family members and friends may feel a continuing bond with the patient who has died [18], or feel to reconstruct their understanding of the deceased patient's role in the network of their family and community relationships as a result of the death [26]. Dual process theory [47] suggests that bereaved family members often shift between forward-looking restorative actions, planning for the future, and backward-looking actions focused on the loss. Evidence suggests that most people do not require extensive bereavement care,

and attempts to assess their need at an early stage do not always identify serious needs, which only become apparent at a later stage. Also, potential users of bereavement services can be more effectively helped once they have become aware of their needs and committed themselves to receiving help [48]. There are ethical and practical difficulties in communicating across the boundary between the patient's care and the family's bereavement care. This is because the patient is the person who has given informed consent to the provision of palliative care and their family needs to give informed consent to their referral for bereavement services, especially if these are not part of the palliative care service, and to the transfer of records and information drawn from them [41].

## Interprofessional Communication Issues

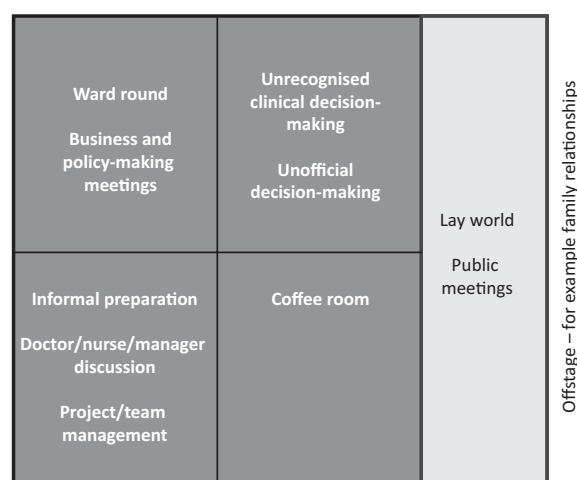
Difficulties with communication, decision-making and power relations among professionals working together is a well-documented issue in integrating health and social care services generally [21]. O'Connor and Fisher's [27] Australian study of conflict between nurses and doctors suggests that where there is a contested area of expertise, role boundaries are often blurred, and several different professions stake claims for their profession's expertise in this field. Specialists such as psychology, spiritual guidance or social care claim that their expertise and knowledge is essential to successful work in this area of palliative care, while members of core medical and nursing teams minimise the knowledge of these profession's knowledge.

Interpersonal factors may also be relevant. Hansford and Monroe [10] identify stereotyping and differences in professional values, codes of ethics and language as important difficulties in multi-professional teamwork in palliative care. Interpersonal factors are affected by underlying social divisions which may also create barriers, including class, status, cultural, ethnic and gender divisions. Examples of these social divisions that are discussed in the research on barriers to teamwork are the reality in many countries that doctors are more often male, of high social status, with long and high-level education, and come from majority ethnic and cultural backgrounds, while other healthcare practitioners are often female, have shorter and lower-level education, their occupations have lower social status and in many countries they are more likely to come from minority ethnic and cultural backgrounds.

Studies of conflict between particular professional groups emphasise how informal and prep-

aration for sharing work outside formal team communication processes can be important, for example in professional role conflicts between social workers and hospice chaplains [55]. Coombs [6] studied power and conflict between nurses and doctors in intensive care, where high-technology medicine thrusts doctors into a publicly dominant position. Her analysis (Fig. 2) distinguishes between official and unofficial clinical decision-making in the 'front stage' area, for example, in encounters with families and patients wards. An official decision might be to use a particular medication or medical intervention, while an unofficial decision might be to calm an agitated patient or worried relative. In the 'back stage' area, these processes are facilitated and smoothed by informal preparation and by non-official discussion to help align attitudes and interests in the coffee room or through various social networks.

One of the most important interprofessional issues in palliative care is communication around the transfer of patients between core staff who are in regular, even daily, contact with patients and families, and specialist staff, such as social workers, psychologists and psychiatrists, physiotherapists and occupational, speech and language, arts and complementary therapists who are more on the periphery of services [33, 38]. While patients may be most at ease in discussing emotional and spiritual issues with staff whom they know well and have confidence in already, core staff may not feel that they have the expertise or time to explore issues about the patient's social relationships, mental health or whole-life spiritual issues in the time available to patients at the end of life [51]. The manner and focus of healthcare professionals



Source: [6]; adapted

**Fig. 2.** Clinical decision-making on and off stage

**Ryc. 2.** Podejmowanie decyzji klinicznych w zespole i poza nim



and their focus on clinical decision-making rather than broader issues of patient care, and patients perceiving trustworthiness and integrity in how professional communicate with them, are important factors in successful professional patient relationships [16, 22]. Moreover, Randall and Downie have argued that patients have not given consent to services beyond medical and nursing care, informed consent to engaging psychosocial, spiritual, supportive and other staff needs to be handled appropriately.

Important issues arise about understanding and communication between medical and psychosocial caregivers. The extent to which psychosocial and medical interventions can support each other is considerable. For example, while pain management seems mainly a medical function, the philosophy in palliative care is that pain usually includes psychological and spiritual elements. Patients experience uncertainty about how to access psychosocial services, but managing the effects of patients' pain on their families and on their psychological and social well-being are important social-work roles in this field that may not be well understood by doctors, nurses or patients [5]. A small American study by Oliver et al's [30] indicates that caregiver assessment and intervention can be an effective way of managing pain, but is often neglected by healthcare practitioners in favour of working directly with patients. A study by Hendrick et al's [12] of the introduction of psychosocial practice in a hospital medical oncology team showed that conventional ways of providing psychosocial care were in tension with more public interactions in a busy hospital ward. Examples of practices that were problematic included the counselling convention of uninterrupted private sessions as opposed to shorter bedside or corridor consultations in the ward; having psychosocial case records containing extended accounts of personal non-medical information as part of a wider system accessed by different professions; ward rounds involving a large meeting of ward staff rather than a team specifically focused on one particular patient; and different attitudes towards touch, which was commonplace in nursing and medical care but unusual in psychosocial care. Such important differences in practice conventions had to be worked through and accommodated.

## Dealing with Team Communication Problems

While there is a considerable number of small-scale studies and commentary in the literature, robust research on successful models of practice

that enhance multidisciplinary practice in palliative care is not yet available [4, 8, 23]. Extensive research on teamwork in the UK National Health Service [2] did not include palliative care teams, but identified four main priorities in successful teams more generally: clear shared aims; active participation, at least weekly; a commitment to quality; a commitment to support of innovation.

A small German study by Jünger et al. [15] confirmed many of these points in palliative care.

The value of advance care planning as part of end-of-life care was discussed above. It provides early concise, comprehensive planning of patient care as people first enter the care system and enables them to think through and provide guidance to professionals about their preferences at an early stage. This has been shown to improve the capacity of services to respond to patients' preferences. Structured programs to coordinate non-specialised care in hospitals and community health services and care homes, such as the Liverpool Care Pathway and the Gold Standards Framework, are effective [35, 50]. Oliver and Peck [29] show that collaboration between social workers and other palliative care staff is enhanced by good communication, mutual trust, distinguishing clear roles, making joint visits and working jointly with patients and their families, team-building activities and managerial interest and support for collaboration.

Youngworth and Twaddle's [56] professional literature and research review identified a range of barriers to effective interprofessional team functioning:

- a breakdown in or lack of communication is an important cause of errors in patient care;
- poor communication can result from geographical barriers and lack of time;
- the team leader's professional discipline may inhibit communication. The major division is that a focus on medical or psychosocial information may exclude the other;
- an organisational structure that promotes hierarchy and concern for status can hinder effective team functioning;
- the absence of clear roles impedes teamwork. However, especially in areas such as palliative care, roles are blurred [28], and careful provision for consultation between professionals may be helpful;
- a lack of interdisciplinary team training and failure to integrate interprofessional work into professional education contributes to barriers.

The three main approaches to improving team work [33] are:

- group development approaches, which emphasise building interpersonal relationships with-

in the group of people who regularly work together. The problem is that this may exclude members of the peripheral team or wider networks of connections and can seem like self-absorption in internal concerns. It needs to be balanced with work in the wider network of interagency and interprofessional relationships [32];

- knowledge management approaches, which emphasise identifying and building respect for the individual expertise and contribution of each profession involved in individual cases. Leaders need to ensure that all the team members can contribute their specialist knowledge and planning to a shared plan that allows the whole team to meet their professional responsibilities and that includes shared actions [31];

- everyday teamwork, which emphasizes managing and leading teams to respect the contribution of all the professionals as people working together, acknowledging the knowledge and role of each, and communicating regularly through shared records, interpersonal reporting and team meetings focused on patients' needs [33].

Partnership approaches to cooperation among organisations is increasingly proposed as a response to these issues [34]. These approaches involve local interagency service planning and intra-agency policy and management structures that give priority to, and seek to remove barriers to, service partnerships. Appointing link staff has been found effective in acute hospital settings [7]. Blacker and Deveau [1] argue that in hospital palliative care teams organisational and leadership commitment to team structures and role resocialisation that facilitate partnership among different specializations and organisations is a crucial prerequisite to effective practice. They also emphasise the importance of involving the patient and family in the team, creating interprofessional care plans, clearly articulating each team member's role, competencies and the scope of their practice in each case. Teams should expect and be prepared to grapple with struggles among team members, rather than seeing these as dysfunctional. It is also useful to ensure that there are opportunities for individual professional development, and protocols for information sharing with other professionals and external service providers.

Providing communication skills training is successful in promoting improved communication with patients and as a basis for improving multi-professional practice. This includes:

- training, policy and organisational structures that support interdisciplinary practice [3, 27]. Training can increasingly be offered online [9];
- training in developing professional skills in such areas as 'breaking bad news' and working

with patients more generally is effective [52], and can be delivered successfully in interprofessional settings [43];

- an extensive end-of-life communication skills project in the UK successfully provided communication skills training to senior medical, nursing and social work staff and was well-evaluated by participation and their agencies. Success required matching courses to the needs of attenders, ensuring that their agencies supported their participation in the training, and an organisational environment in which the skills gained could be used effectively [25].

## Conclusion

This paper reviewed a range of issues about communication in palliative care teams. Three areas of communication are important:

- communication between a palliative care service and other health and social care services in which it is nested, and among different professional networks involved with patients and their families;

- communication with patients, their families and their communities about death, dying and bereavement, all issues where important cultural, social and spiritual beliefs and experiences affect people's reactions. People may be unaccustomed to communication about these issues and therefore find open and positive communication difficult, but openness is crucial to providing good palliative care;

- communication between members of the care team from different professional backgrounds across organisational boundaries between services.

While death is a natural process, the achievement of the medical profession over the past hundred years in defeating the common causes of early death means that many people do not encounter death and bereavement frequently in their life experience. Social expectations about how to react to the death of someone close and important to us have therefore become more private and more medicalised; people have often never gained the skills to communicate about death and bereavement.

A good death is facilitated by effective advance care planning as part of end-of-life care in everyday health and social care, because this makes it easier to meet the patient's and family's preferences. It is important in end-of-life care for all non-specialised health and social care personnel to have the communication skills to take opportunities to engage with people in discussing their care preferences as they enter the care system with

a long-term condition, or as they become more frail in old age. Even if this opportunity has been missed, some advance care planning discussions are possible when advanced or terminal illness is diagnosed, perhaps more focused on advance decisions about treatment.

Establishing partnerships among services in planning and coordinating care for people experiencing increasing frailty in old age or suffering a long-term medical condition is an important basis of effective multi-professional palliative care. Professional services need to be carefully interwoven with the role and preferences of family caregivers, who often bear a significant burden of care at the end of life. Significant social and professional barriers to communication exist among members of the palliative care team, and between the palliative care team and wider professional and service

networks. Training in communication, particularly multi-professional training, has been shown to be helpful in overcoming these barriers.

While developing group relations among team members can be helpful, it is important not to exclude personnel in wider networks or who make a more occasional contribution to palliative care. A 'knowledge management' approach, which concentrates on integrating the knowledge and contribution of every professional engaged with a patient and family into a coherent treatment plan, and which also recognises specialist roles, is a valuable way of focusing teamwork on the needs of patients and their families. A focus on facilitating people working together everyday and ensuring that their different contributions are respected is a continuing responsibility for leaders and every member of palliative care teams.

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