

# Delivering Quality Care for Palliative Care Patients

Sue Healy & Prof. Liz Reymond



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Registered Nurse Sue Healy is passionate about end-of-life care, and Professor Liz Reymond specializes in palliative care. Here, they discuss a joint project aimed to aid those who care for palliative patients at home.



**As a starting point, can you tell us what led you to your respective interests in palliative care?**

[SH] Caring for the dying has always been an interest of mine. My passion for palliative care began early in my nursing career. Working as a community nurse, I was exposed to many home deaths. It was an absolute privilege to be invited into someone's home and to be involved in their care, as we prepared the family and friends for the journey ahead, especially as end of life for the patient approached. It was here that I recognised that palliative care was about holistic care supporting the family unit, delivering regular and ongoing assessment, and importantly administering effective pain and symptom management.

[LR] I started my career as a General Practitioner [and], during this time, developed a real interest for palliative care. I have been part of a team that successfully established a large palliative care service that encompasses dedicated hospice beds across several hospitals within the Metro South district. As well as a consultative service at a large tertiary hospital in Brisbane and three community palliative care sites. I established the Brisbane South Palliative Care Collaborative, which is the research and service development component of the service. The collaborative has been successful in gaining funding to pursue research in the area of palliative care, and, the Caring Safely at Home Project was one of the fruits from this endeavour.

**Were there any significant roadblocks to completing this project?**

Not really. Ethics approval was granted from several ethics committees. One ethics committee initially challenged the practice of teaching laycarers to administer opioid injections, as they were concerned about the interface between effective pain management and euthanasia. The Guidelines for the Handling of Medication in Community Based Palliative Care Services in the Queensland document endorsed by the appropriate peak bodies assisted in the process.

Another issue was trying to access a community pharmacist to prepare the medications for the patients that were assigned to the pharmacy arm of the project. Very few community-based pharmacies had the capacity to prepare injections under sterile conditions. Eventually, a private hospital pharmacy agreed to prepare and label the medications. The project coordinator collected the medications daily and delivered them to the patients as required.

You received funding for this project from the Australian Government Department of Health and Ageing. Are the needs of laycarers a new concern for the Australian government and have they tried to address these issues in the past? Periodically, the Australian Government allocates funds for projects that may specifically address laycarers concerns. However, the needs of this group are increasing significantly and funding is difficult to find especially in the area of community services that aims to support laycarers (domestic support, respite – especially as end of life approaches, personal care, packages of care, and the like). In the future, this may prevent laycarers from being able to stay at home.

**The randomised controlled trial found that laycarer confidence increased regardless of who prepared the medications. Did this result surprise you?**

Yes. It was considered that the RCT may show that laycarers who prepared their own injections would be less confident than if the registered nurse or pharmacist prepared the injection. However, it was identified that laycarers' confidence was not influenced by who prepared the injection and, as the laycarers gained experience with injecting their level of confidence increased. This shows that, if laycarers are given standardised and appropriate information and training, they can acquire the confidence and skill to safely prepare, store, and administer subcutaneous injections to manage symptoms as they arise.

**What is the next best step to continue addressing problems in home palliative care in Australia?**

Support Palliative Care peak bodies to continually lobby the Government for improved funding. The aim is to increase funding for palliative care services across Australia so that there is equity and access to high quality palliative care for all patients, as they require it.

**Do the two of you plan to continue working together?**

Yes, we will continue to work together to promote the use of the resources to support laycarers. Part of our advocacy is to allow patients and their caregivers easier access to palliative care service with similar programs as this.

# Educational Package Improves Home-Based Care Palliative Care Patients

Australians who live in regional and rural areas often have difficulty accessing palliative care services. To address this issue, Prof. Sue Healy and Prof. Liz Reymond have recently developed a suite of new tools to teach at-home caregivers to administer subcutaneous injections to those palliative patients whose symptoms need control.

## PALLIATIVE PROBLEMS

The choice to receive care and die at home is an important freedom for patients. It gives them the chance to maximise the quality of the time they have left and spend it with their families and friends in the environment of their choice. However, this choice often means that a family member, or another person close to the patient, is put in charge of care that can extend to symptom control.

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**...as the laycarers gained experience in administering injections, their confidence level also increased, as statistically demonstrated by the experiment. This proves that if laycarers are given standardised information and training, they can acquire the confidence and skill to safely prepare, store, and administer subcutaneous injections as symptoms emerge.**  
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This person is known as the laycarer. Often, the laycarer may lack background knowledge to provide extensive medical care to the patient. While this situation can be distressing the stress can be further exacerbated by lack of a supportive infrastructure. Sue Healy, RN, and Prof. Liz Reymond have worked to fix this problem in Queensland, Australia by creating an educational package called Caring Safely at Home. The goal of the project is to teach laycarers how to properly administer medications by subcutaneous injection to relieve patient's symptoms if they emerge. They also trained RNs to use the educational package to ensure laycarers received consistent information in their areas of medication management.

As in many other parts of the world, laycarers in Queensland, particularly those who live in the regional and rural areas, have difficulty getting access to medical professionals and institutions. Medical centres in regional and rural locations may be too far from their residence to access in times of emergency. Some, but not all, of these centres offer over-the-phone services 24 hours a day. However, there is also the issue of some centres being understaffed or closed at night, despite the need for round-the-clock care for palliative patients.

Laycarer health education is also a concern among medical professionals in Queensland. Laycarers can often be misinformed about aspects of health care such as the benefits of opioids in palliative care. During their research, Healy and Reymond experienced resistance from laycarers to administering opioids because they believed they were too dangerous. Many believed that opioids were inescapably addictive if taken every day, even if used as prescribed. As a result, patients maybe undertreated. With the proper education, however, Healy and Reymond hope to provide laycarers with the tools to provide high-quality care autonomously.

## EDUCATING OTHER NURSES

Education for health professionals working with laycarers is just as crucial to the success of the Caring Safely at Home project. While palliative care specialists have been unofficially teaching laycarers how to properly administer subcutaneous injections for a long time, some healthcare professionals and organisations believe that subcutaneous injections should not be administered by laycarers at all. When Healy and Reymond invited palliative care sites to participate in their trial, they were met with some resistance from healthcare professionals. These professionals required



clarity when it came to the legal ramifications of teaching laycarers to administer subcutaneous injections at home. The researchers recognized the need for official documentation outlining the legality of managing medication in the community. This is the reason why the "Guidelines for the Handling of Medication in Community-Based Palliative Care Services" was developed. Luckily, specialist palliative care nurses had already begun drafting these guidelines, which contributed greatly to the project. The guidelines were approved by the Nurses Registration Board of Queensland, the Safety Medication Management Unit, and the Environmental Health Department within Queensland Health.

Even when the randomised controlled trial to examine the effectiveness of the program had commenced, some service providers were still reluctant to ask laycarers to participate in the trial. They felt that subcutaneous injections were too difficult a task for non-medical professionals. Healy and Reymond point out that this attitude only exacerbates the problem they are trying to solve. If a laycarer runs out of a medication at night or on a weekend, the patient will likely be unable to receive any care at all. That may result in hours or days of excruciating pain or other symptoms or an unwanted admission to hospital. It is less stressful for laycarers if they are prepared for this situation by learning how to manage symptoms by administering medications themselves.

## CARING SAFELY AT HOME EMPOWERS LAYCARERS

The program itself includes helpful charts, lists, and other tools to help laycarers at home. There are five illustrated, step-by-step charts, which exhibits the different medical techniques in the program. The first chart demonstrates how to open and draw up from a glass medication ampoule to measure dosage. The other charts guide laycarers through four different techniques including both blunt needle and needle-less injections. Laycarers also received a colour-coded medication labelling system to easily track which medications are appropriate for different symptoms and a diary to document each injection to make patient treatment monitoring easier for RNs. A medication booklet provides laycarers with information on symptom control and addresses frequently asked questions and common myths. Also included is a DVD giving laycarers a visual guide for how to properly prepare, store, and inject medications. RNs used the practice demonstration kit included in the package to physically show patients how to give subcutaneous injections during the face-to-face training session. The included competency checklist allows RNs to check laycarer competence.

One important goal of this project was to ensure that laycarers felt capable and competent to provide quality care. To test their confidence, Healy and Reymond implemented the program in 24 sites that provided palliative care. Scattered across southeast Queensland, these sites were located in urban, regional, and rural settings. Two hundred seventeen RNs were trained to educate laycarers about how to use the resources in the package. To gauge the results, 106 laycarers completed two questionnaires: one after the training session and one after they had more experience giving injections. The questionnaires asked participants to rate their satisfaction with various aspects of the program on a seven-point scale. The results showed laycarers being satisfied with the program, with each question receiving an average of 5.9 out of 7 for both sets of questions. Fifty-three RNs completed the questionnaires at the conclusion of the study. Nurses also responded positively to the program, believing that it explains all the necessary information well and addresses the needs of laycarers.



A randomised controlled trial examined whether laycarer confidence was affected by who prepared the medications to be injected. Ninety-four laycarers were randomly assigned to one of three groups. In the first group, medications were prepared by laycarers. In the second, they were prepared by RNs. For the third group, the medications were prepared by a pharmacist. While laycarers in all three groups became more confident in their ability to administer injections over time, there was no significant difference between these three groups. Of the 1306 injections analysed, the correct medication was given each time. Implementation of the package and analysis of the RCT reveal that laycarers are capable of confidently administering subcutaneous injections at home. For those who care for loved ones as they reach the end of their lives, the benefits of this program are tremendous.

## Researcher Profile



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Sue Healy earned her Bachelor's degree in Health Science Nursing, and her Masters of Nursing Chronic Disease and Palliative Care.

Prof. Liz Reymond began her education by earning a Bachelor of Medicine, Bachelor of Surgery, and received her PhD from the Australian National University.

Healy and Reymond continue their careers in the pursuit of finding new ways to improve care for patients with chronic and end-of-life illnesses, conducting researches that combine and utilise both of their specialisations.

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