

# Innovations umbrella:

**Improving the care for dying patients  
and support for the relatives**

A collection of ideas and experiences from  
the ERANet-LAC CODE project



# ERANet-LAC CODE

## International Care Of the Dying Evaluation: quality of care for cancer patients as perceived by bereaved relatives



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If anyone would wish to use the 'CODE'™ questionnaire, enquiries should be directed to Dr Catriona Mayland, [c.r.mayland@sheffield.ac.uk](mailto:c.r.mayland@sheffield.ac.uk), so a Material Transfer Arrangement can be facilitated. CODE™ should not be altered without request.

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# CONTENTS

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<b>Foreword</b>	<b>4</b>
<b>Introduction</b>	<b>5</b>
<b>Educational initiatives:</b>	
'Tree of Knowledge'	6
'Itinerant Box'	7
'CINE HES'	8
LEZ TALK about death	9
<b>Communication initiatives:</b>	
Improving emotional support and communication about the dying phase: a quality improvement project in a Polish hospital	12
Creating a 'safe place' for end-of-life communication with relatives in hospital	13
Improving patient and carer experience at the end of life by providing information about hydration	15
A peaceful place for serious conversations	17
<b>Organisational improvement:</b>	
The better handovers, the better care at the end of life	19
<b>Bereavement support:</b>	
A nurse-led bereavement support initiative	21
Palliative care out-patient follow-up room on Tuesdays: hosting bereaved relatives	22
Babies photo memories	23
<b>Partners</b>	<b>24</b>



# FOREWORD

## “How people die remains in the memories of those who live on”

This oft-cited quote from Dame Cicely Saunders touches upon two central aspects of palliative care: the importance of high quality end-of-life care, and the family as the unit of care. Even with palliative care being integrated ever earlier in the disease trajectory, the calling to provide good care for dying patients and their relatives is still vital and valid, whatever healthcare level or setting.

The International Collaborative for Best Care for the Dying Person brings together multidisciplinary practitioners in palliative and end-of-life care who wish to build the evidence base for best care for dying patients through collaborative knowledge transfer, clinical excellence, research, service innovation and quality improvement. The vision of the Collaborative is for a world where *all* people experience a good death as an integral part of their individual life, supported by the very best personalised care.

The ERANet-LAC CODE project (2017-2020) originated from the International Collaborative and engaged three South American and four European partners. The project aimed to develop the CODE™ (Care Of the Dying Evaluation) questionnaire into an international tool and use it in an observational, cross-sectional post-bereavement survey to assess the current quality of care for dying cancer patients at an international level. In the last phase of the project, the aim was to use the survey results to improve the care by conducting local quality improvement projects.

This booklet presents a collection of ideas and experiences from the ERANet-LAC CODE project. Most of the presented ‘cases’ are examples of how results of a post-bereavement survey were used to improve the quality of care, in other words: innovations for putting research results into practice.

We hope this collection will inspire and motivate palliative care providers across the world to improve the care for dying patients and their relatives. We are happy to receive any comments to the contents, or to place your local project under our ‘umbrella’.

Bergen, Norway, September 2020

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# INTRODUCTION

Care for dying patients and their relatives involves many different aspects, such as nursing care, communication, symptom control, and emotional and spiritual support.

In order to improve the care, we need to be able to assess the current quality of care. One internationally recognised method for evaluating care for dying patients is to ask bereaved relatives about their perceptions, using post-bereavement surveys.

The ERANet-LAC CODE project conducted an international post-bereavement survey, recruiting participants from 22 hospitals in Argentina, Brazil, Germany, Norway, Poland, UK and Uruguay. The results showed that the relatives generally had good perceptions about the care for dying patients and support for family members. Nevertheless, areas that could be improved were identified in all countries.

This booklet presents the quality improvement projects that were carried out in response to the results from the CODE International Survey. Projects in Argentina and Poland were part of the original project plan, but this collection also contains experiences from other project partners. A few of the innovations were introduced at an earlier stage of the project, but are included to illustrate a variety of approaches and 'cases' from different levels of palliative care development.

The aim of this publication is to give examples of how research and measurement results may be transferred to practical improvements. By sharing ideas, experiences and challenges we hope to inspire colleagues both to assess and to improve the care they provide to dying patients and their families.

Happy reading!



Education  
Organisation  
Communication  
Bereavement support

# 'Tree of Knowledge'

A creative way to disseminate the concepts of palliative and end-of-life care to staff, patients and relatives in a Brazilian hospital

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## Context and Driver:

Palliative Care is a young discipline in Brazil. In 2016, an interprofessional Palliative Care team was set up in our hospital. The next year, we joined the CODE (Care of the Dying Evaluation) project, with goals to improve the quality of care and quality of life for dying cancer patients. We had to disseminate the concepts of palliative and end-of-life care to all staff, patients, and families at the hospital. However, the employees reported difficulties in leaving their duties to attend team meetings, so other actions were necessary to involve the institution as a whole (continuing education).



## Aims & Intended Outcomes:

- To disseminate the concepts of palliative and end-of-life care to all staff, patients, and families at the hospital
- Disseminate the concepts in a creative way, easy to understand

## Process:

- The team designed and developed the 'Tree of Knowledge'
- Paper butterflies were distributed, and everyone was encouraged to leave messages or doubts about palliative care



## Benefits:

- Palliative care was demystified as well as propagated in the hospital
- The 'tree project' created a background for introducing the i-CODE project

## Challenges:

- To reach everyone
- Work with concepts on all shifts
- Clear up any doubts that had arisen

## Key points:

- Effective communication with everyone
- Be present on all shifts to spread the idea

# 'Itinerant Box'

A creative, interactive way to disseminate the concepts of end-of-life care to staff in a Brazilian hospital

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## Context and Driver:

Palliative Care is a young discipline in Brazil. As part of the i-CODE project (2017-2020) we wanted to educate staff about concepts and principles for end-of-life care. Since employees reported difficulties in leaving their duties to attend educational sessions, we decided on outreach activities.

## Aims & Intended Outcomes:

- To disseminate the concepts and principles of end-of-life care to all staff at the hospital, in a creative, engaging manner
- Staff able to provide holistic, competent end-of-life care



## Process:

- The team designed and developed the 'Itinerant Box'
- The box contains objects related to end-of-life issues, such as:
  - a clock – to talk about time (time left and quality of that time)
  - a family photo – to talk about relationships and support for family members
  - a scale of justice – to talk about patient rights
  - a dish – to talk about food and drink at the end of life
  - an oxygen catheter – to talk about breathlessness
  - a morphine ampulla – to talk about pain management
  - a cross – to talk about spirituality



The "Itinerant Box" is taken to all hospital units by the Palliative Care team according to a schedule. The employee's eyes are blindfolded to draw an object from the box. After the draw, the employee tells his/her experience related to that object in end-of-life care.

The Palliative Care team can adjust the concepts and understanding and provide guidance as needed.

## Benefits:

- End-of life care is demystified and propagated in the hospital
- The 'Itinerant Box' created a background for the work on the i-CODE project
- An interactive way to teach palliative care knowledge and skills and influence attitudes

## Challenges:

- To reach everyone
- Work with concepts on all shifts
- Clear up any doubts and misunderstandings

## Key points:

- Effective communication with everyone
- The main thing is to let people talk about their feelings and ideas and then carefully adjust any misconceptions

## ‘CINE HES’

## Using films to disseminate the concepts of palliative and end-of-life care

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## Context and Driver:

Palliative Care is a young discipline in Brazil. In 2016, an interprofessional Palliative Care team was set up in our hospital. The next year, we joined the CODE (Care of the Dying Evaluation) project, with goals to improve the quality of care and quality of life for dying cancer patients. We had to disseminate the concepts of palliative and end-of-life care to all staff of our hospital. We decided to use a number of different approaches, including the arts.



### **Aims & Intended Outcomes:**

- To disseminate the concepts of palliative and end-of-life care to all staff, patients, and families at the hospital
- Disseminating the concepts in a creative way, easy to understand

## Process:

The team developed a local cinema: 'CINE HES' (Cinema HES – HES is the abbreviated name of our hospital), showing films that address death and end-of-life issues

## Benefits:

- Encouragement to talk about death
- Propagating palliative care

## Challenges:

- To reach everyone
- To find suitable films

## Key points:

- Effective communication with everyone
- Be present on all shifts to spread the idea

# LEZ TALK about death

Blended learning about end-of-life conversations with relatives, for medical students in the last academic year

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## Context and Driver:

We used the results of a post-bereavement survey in 7 European and South-American countries about care for dying cancer patients in hospital in order to improve the quality of care.

Drivers for the current project were that 23% of relatives of dying patients were not informed about impending death, and of those informed, 37% did not get information about what to expect when their relative was dying. We also know that relatives trust that newly qualified doctors ('career starters') are capable of having this type of conversations.

## Aims & Intended Outcomes:

- In young doctors:
  - to feel confident with disclosure of a patient's impending death to her/his relatives
  - to be familiar with explaining regular phenomena of the dying phase to relatives and friends accompanying a dying patient
  - to learn how to deal with the burden of caring for a dying patient
- In superiors and management: Generate awareness of the necessity and benefits of skilling up trainees to have these conversations with relatives.



## Process:

Undergraduate medical students of the last academic year (practice year) are offered blended learning about how to talk about impending death and the dying process with relatives. The students had received some palliative care training one year earlier. Now, they continue with an online introductory lecture about the dying phase, and accompanying textbook contents. At the beginning of the practice year, they receive basic communication training with professional actors in role plays, supervised by an experienced palliative care physician. Repeated training once or twice in small groups as well as individual supervision are offered during the practice year.

Thanatophobia and self-confidence with communication are assessed at baseline and along the course until the end of the practice year. Additionally, empathy and burnout are assessed at baseline and at the end of the year.

Bereaved relatives are offered to participate by responding to the i-CODE questionnaire 6-8 weeks post bereavement, in particular to the items related to communication about impending death.

A steering committee with undergraduate medical students, actor, and palliative care specialist supports the development of the curriculum regarding feasibility, content, material, and execution.

Project information to staff (emails, staff meetings).

### Benefits:

- Longitudinal approach, supportive for advanced learning level and reflective working, accepted for implementation in the curriculum
- Transition of the reflective attitude to other work areas
- Students gaining confidence in informing relatives about the dying phase
- Students discussing their own vulnerability as a person rather than physician

### Challenges:

- Work load of the practice year; some students willing to follow up were not released from their ward duties
- Some students disappointed by other training during the practice year did not attend the course
- Impaired flow of information due to staff shortage and unclear roles and duties in the academic management
- Data protection concerns compromised contact with students

**“What I learned, helps to have a good ending for all – the patient, the relatives – and me”**

**(student)**

### Key points:

- Take time for the administrative preparation: Install multiple secure ways of information about access to the course, course schedule, and outcome assessments
- Involve students, let them participate in course responsibilities, e.g. course evaluation
- Make use of social media and blended learning
- Be aware of the costs (Germany: 10,000 € for 12 months for 30 students (330 €/ student))





# Improving emotional support and communication about the dying phase: a quality improvement project in a Polish hospital

## Contacts:

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## Context and Driver:

We used the results of a post-bereavement survey in 7 European and South-American countries about care for dying cancer patients in hospital in order to improve the quality of care.

In general, the results for the i-CODE survey indicated that perceptions about care for dying patients in Poland were very good. In a few areas, however, the mean scores were below the upper quartile. One area was emotional support, with 28% of relatives scoring 'poor' or 'fair'; another was information about the dying phase. These two areas were selected for a quality improvement initiative.

## Aims & Intended Outcomes:

- To improve the emotional support provided to the relatives
- To improve the communication between staff members and relatives, especially concerning the dying phase

More specifically our objectives were:

- To produce a **leaflet** providing information about the dying phase and telling the relatives about available emotional support
- To hand out the leaflet to at least 60% of the families during the three-month project period
- To assess the usefulness of the leaflet from family and staff perspectives, using field notes and short evaluation meetings

## Process:

- We produced the leaflet and piloted it in relatives and staff. The project was anchored on the ward and with the management team.

- Psychologists handed out the leaflet to relatives of dying patients. During usual care procedures, relatives were asked for their opinion about the leaflet.

**"Thanks to the leaflet, we found out that mom is dying, and that these are natural symptoms of death"**

## Benefits:

- Leaflets were handed out in 62% of deaths (38/61). 33 field notes were taken.
- 30 relatives reported to have read the leaflet and rated it as helpful
- 14 relatives contacted the psychologist for support
- Staff found the leaflet helpful in their communication with the relatives, and reported about a calm atmosphere on the ward

## Challenges:

- Staff members need to be trained to be able to discuss the contents of the leaflet
- A psychologist or other skilled staff member (social worker, chaplain) must be available for emotional support

## Key points:

- Hand out the leaflet only to relatives of patients that are expected to die, do not leave the leaflet for free access
- Educate staff about the importance of good, empathic communication
- Investing time and energy in designing a leaflet and creating a simple training system and standard procedure lowers the time needed for conversations with relatives and raises the quality of the care

# Creating a ‘safe place’ for end-of-life communication with relatives in hospital

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## Context and Driver:

We used the results of the i-CODE post-bereavement survey about care for dying cancer patients in hospital to improve the quality of care.

In Argentina, the areas where care was perceived less well were mostly related to relatives’ support, information and decision-making, and environmental factors:

**“I never felt more lonely than on those weekends when nobody was there, an absolute orphanhood”**  
(bereaved relative)

## Aims & Intended Outcomes:

- To implement a practice guideline for family meetings during the patients’ last days of life, in order to improve both the quality of the communication and the environment
- To assess the immediate direct impact of these changes from a family and healthcare professional point of view, by use of action research, including brief, structured interviews

## Process:

- We used focus groups with staff members, relatives and volunteers to identify strategies to support change in institutional culture around dying patients and communication with the relatives
- SWOT analysis was used to facilitate processes of change – an analytic method to describe **S**trengths, **W**eaknesses, **O**pportunities, and **T**hreats of the planned and ongoing process

- We set a target to apply the guideline and conduct family meetings in 60% of deaths during the project period
- We conducted 24 family meetings during the project period (24/51 deaths), 15 cancer patients and 9 non-cancer patients

## Benefits:

- Family members were involved in advance care planning. They acknowledged privacy and compassionate communication when death was approaching.
- We reached our goal in that 62.5% of family meetings in the last days of life of in-patients with cancer took place in a ‘safe space’, meaning a ‘safe and confident communication environment’ ensuring privacy and clear information as required, based on best communication practice
- Participatory action research assumed family competence and cultivated a respectful and reciprocal relationship between healthcare professionals and families
- Staff members’ self-report showed improved confidence, knowledge and skills regarding ‘difficult conversations’

**“They reassured us. Everything they told me was going to happen, happened. It was quiet; they explained the reason for everything. I felt well, accompanied”**  
(bereaved relative)

## Challenges:

- In Argentina, overall perceptions indicate that care for dying patients and support for their families are good. However, less than 10% of seriously ill and dying patients have access to palliative care.
- This quality improvement project demonstrated that when involving bereaved relatives in the action planning, key changes may be facilitated within the clinical environment of individual organizations, such as a teaching hospital

## Key points:

- We used the quality improvement model '**Plan-Do-Study-Act**'. This model is particularly useful to test a change on a smaller scale, assess its impact and then use the learning from the previous cycles in a structured way before wider implementation.
- Forming a **good team** is critical to a successful improvement effort
- **Involving bereaved people** in the action planning was a key to success

- As proof of concept, the immediate direct impact of the changes was assessed from a family and healthcare professional point of view. These findings are not generalizable, but should encourage staff caring for dying patients to promote quality improvement initiatives.

## PAMPA:



Permite detenerse, pensar, evaluar y cambiar



Asegura la prescripción anticipada para el alivio de los síntomas



Incluye a la familia en el cuidado



Evita maniobras invasivas innecesarias



Pone atención en los detalles



Reevalua cada 4 hs el proceso dinámico del paciente.



Se basa en una buena comunicación, clara y comprensible



Requiere del registro multidisciplinario del cuidado

Right illustration: Panel from pamphlet used when teaching nursing staff about PAMPA, an integrated care plan for the dying phase.

# Improving patient and carer experience at the end of life by providing information about hydration and what to expect when someone is dying

## A quality improvement project

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### Context and Driver:

We used the results of a post-bereavement survey in 7 European and South-American countries about care for dying cancer patients in hospital in order to improve the quality of care.

Drivers for this project were that 41% of bereaved relatives would have preferred a discussion about giving fluids during the period when their family member was dying, and 43% of bereaved relatives would have preferred a discussion about what to expect when their family member was dying.

### Aims & Intended Outcomes:

- All patients (where appropriate) and those identified as important to them should be offered a conversation about hydration in the last days of life
- For all patients who are dying, patients (where appropriate) and those who are important to them should be given the hydration patient information leaflet to support discussions about this issue in the last days of life
- All staff should be aware and confident in opening a conversation about hydration in the last days of life

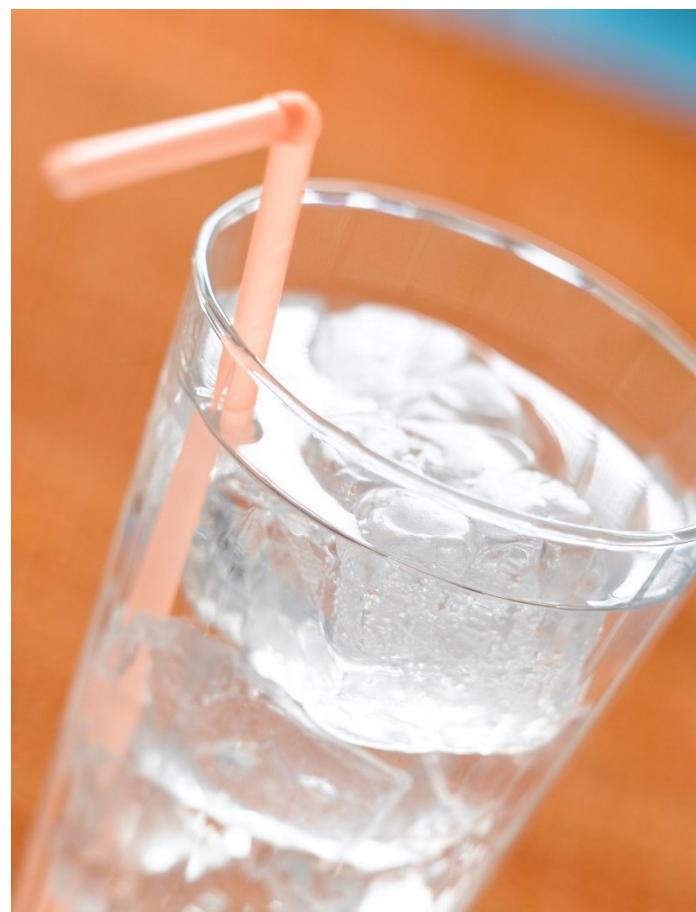
### Process:

We completed a retrospective **audit** of 30 case notes of patients who had died. We reviewed the case notes to look for conversations about hydration and whether

written information was given regarding an individual plan of care for the dying patient, specifically with regards to a hydration plan.

We also completed a **survey** of healthcare professionals from 5 wards in the acute hospital. Four of the wards were chosen because the Specialist Palliative Care Team receive some of the highest numbers of referrals from them. We also included the academic Palliative Care Unit in the hospital.

We introduced a patient and carer written information **leaflet** about what to expect in the last hours to days of life, and we sought user feedback of this information leaflet. The purpose of this information leaflet was to support conversations about care of the dying with patients and their families.



## Benefits:

- This project highlighted the importance of meeting information needs for families of dying patients; in particular, issues of hydration in the last hours to days of life
- Concerns from healthcare professionals about causing distress to patients/families when discussing risks and benefits of hydration options can be a barrier to opening these conversations. Further education for all healthcare professionals could help increase their confidence with providing this information to patients/families.

## Challenges:

- It was difficult to ask dying patients and their families to comment on the actual information leaflet given to support end-of-life conversations in

real time due to concern of imposing additional distress to them

- The hospital has a fixed format in which all information leaflets need to be designed, and although the design was not user-friendly, we could not change that.

## Key points:

- When planning the project: Be clear about the objectives for the project, set a realistic timeframe and have a supportive team
- Get buy-in early on in the project from the different wards involved so that they are more likely to engage in the dissemination activities afterwards
- Have a well-defined impact strategy at the start of the project



**NHS**  
The Royal Liverpool  
and Broadgreen  
University Hospitals  
NHS Trust

### Patient information

#### An Explanation of the Care in the Last Hours or Days of Life for Patients, Families and Carers

Academic Palliative and End of Life Department

The doctors and nurses looking after your relative or friend believe that there has been a change in his or her condition. They believe that despite their best efforts and treatments, your relative or friend is now thought to be dying.

The focus of treatment is to ensure symptoms are controlled. A plan of care tailored to their individual needs and wishes will be used as discussed with you by the doctors and nurses.

All decisions will be reviewed regularly. If your relative or friend's condition improves then their treatment plan will be reviewed and changed accordingly.

#### Questions you may be asking...

In order to reduce the anxiety which often comes from the unknown, some of the typical features of the dying process are explained below. The dying process is unique to each person, although in most cases there are common changes which help to suggest that a person is dying.

#### What will happen about food and drink?

Your loved one may stop eating and drinking. This is a normal process during the last days of life; although it can be difficult to watch this happening to someone you care for. At this time food and drink may not be wanted or needed. Your loved one is not likely to feel hungry or thirsty.

Allowing the person to eat and drink if they wish to do so is important. The ward team will assess if your loved one is alert and awake enough to eat and drink safely. This is not without an element of risk if the person is weak. This is often referred to as "risk feeding" and will be fully explained if this is to be considered. However, caring can be continued in many other ways, such as moistening of the lips or providing mouth care to keep the mouth clean and moist.

When someone stops eating or drinking it can be hard to accept, even when we know that they are dying. It may be a physical sign that they are not going to get better. Decisions about the use of medical treatments e.g. a drip, also referred to as clinically assisted hydration, will be made in the best interests of your relative or friend at this moment in time. Sometimes the benefits of a drip have to be weighed against the risks. If the medical team feel that the fluids are causing more harm than benefit they may discuss stopping the drip. The decision will be explained to you and reviewed daily.

# A peaceful place for serious conversations

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## Context and Driver:

We used the results of a post-bereavement survey in seven European and South American countries about care for dying cancer patients in hospital in order to improve the quality of care.

The results of the survey in our hospital in Montevideo, Uruguay, showed that several participants expressed considerations about the place where bad news was transmitted and the daily report delivered. In view of the fact that most of the hospital wards are shared, various instances of communication were carried out in the corridor, without proper privacy and environment.

Alternatives were sought to correct the situation. The hospital chapel appeared as the best choice for a place to converse in a more private and peaceful setting.

## Aim:

Obtain a suitable place in the hospital for conversations with relatives

## Benefits:

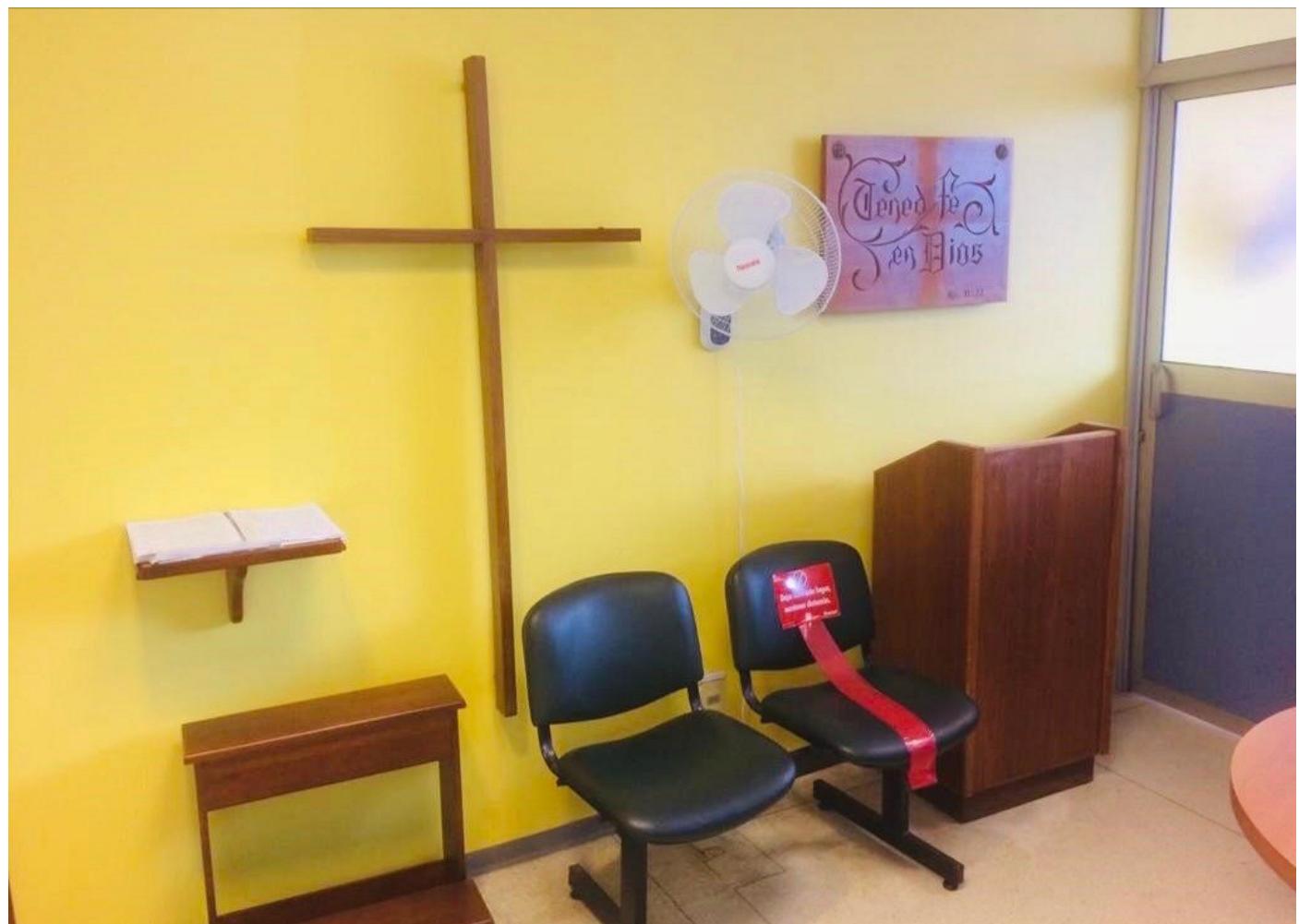
- Environment with more privacy
- Friendlier environment
- Improved communication
- Improved relationship with other hospital services (chaplaincy)

## Challenges:

Optimally, we need more suitable locations for transmitting bad news (one per floor in the hospital)

## Key points:

- Be sensitive to relatives' wishes
- A peaceful environment creates safety and is essential for effective communication





# The better handovers, the better care at the end of life

Introducing IPASS as a communication tool during handovers between healthcare teams caring for dying patients

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## Context and Driver:

We conducted focus groups with bereaved relatives to discuss the results of the i-CODE post-bereavement survey in Argentina. One woman said:

**“I could not obtain rescue analgesics because of bad communications between oncologist and residents, so my husband was in pain until the next morning”**

We acknowledged that this type of miscommunication unfortunately was frequent and could have detrimental effects on symptom control, so we decided to make this our area for improvement.

IPASS is a handover communication tool intended to reduce medical error. It consists of the following parts: **Illness Severity; Patient Summary; Action List; Situation Awareness and Contingency Planning; and Synthesis by Receiver.**

## Aims & Intended Outcomes:

- To improve dying patients' comfort at night at least 60%, on an Oncology ward at a teaching hospital, during a three months' period
- To improve communication between different healthcare teams by using IPASS as a communication tool during handovers (goal: 60%)
- To introduce handovers in the interns' curricula through an educational module about the use of IPASS and basic principles of end-of-life care

## Process:

- Our 3 main drivers to change were:
  - A strong commitment among the Quality and Safety, Internal Medicine and Oncology Departments, ward nurses, volunteers and the Palliative Care team. We conducted several focus groups with these stakeholders to obtain support for and insight into our plan.
  - Our hospital was already using IPASS as a means to improve the transfer of medical information. We planned to use it in ward handovers to ensure our patients were well-known to the intern during night shifts.
  - Starting up an educational module about IPASS and core knowledge about end-of-life care
- As a result indicator we asked the patient's relative(s) the morning after the handover about the patient's comfort during the night

## Benefits:

During the study period, 16 patients died on the ward. Our research team could include 13 of them in this new communication process. Together, these patients represented 24 possible days for getting information about the level of patient comfort during night shifts.



- 65% (47/73) of healthcare professionals on the Oncology ward were trained in using the IPASS
- IPASS was used in 65% of possible handovers
- We obtained 23 out of 24 possible reports showing good level of care. 95% of the reports reflected good symptom control at night and 90% of the relatives were satisfied with the professionals' work to maintain patient comfort.

### Challenges:

- IPASS use during weekends was lower than on weekdays
- The process still depends strongly on the Palliative Care team's commitment to ensure continuity
- There is a continuous need to disseminate basic palliative care principles throughout the institution

### Key points:

- Involving bereaved people in the action planning was vital to pinpoint the area for improvement
- Linking our plans to a major, ongoing hospital project was a key to success
- The Palliative Care team played a central role in the entire process

**“When we called the nurses, they always asked doctors and gave him medications immediately. And they talked to him, ‘we are going to give you something, and you will feel better’”**  
 (relative of patient receiving end-of-life care)



# A nurse-led bereavement support initiative

Follow-up of bereaved relatives by the Department of Thoracic Medicine, Haukeland University Hospital

**Contact:** Prof. Dagny Faksvåg Haugen, Haukeland University Hospital and University of Bergen, Bergen, Norway  
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## Context and Driver:

We used the results of the i-CODE post-bereavement survey about care for dying cancer patients in hospital to improve the quality of care. In free text comments and a subsequent focus group with bereaved relatives, participants reported that they missed follow-up from the hospital ward after the patient had died.

**“After discharge from hospital, the specialist palliative care team called us once a week until my husband died. After that, nobody called. It’s hard to believe, really. I was waiting for a phone call...”**

## Aims & Intended Outcomes:

- Introduce a new procedure to ensure that all relatives of palliative care patients are offered a conversation as a follow-up in bereavement
- Offer a follow-up visit to the ward (optional)

## Process:

- Project information to staff (emails, staff meetings)
- Information sheet to be included in pamphlet to bereaved relatives
- New procedure on the ward to inform about the offer of a telephone call when handing out the pamphlet
- Check list (procedure; relevant topics) and system for documentation and planned appointments (1 hour)

- Education and training
- Decision to document call contents in patient's file

## Benefits:

- After 61 deaths, 37 relatives wanted a conversation. Very few ask to come back and visit.
- Nurses report that the conversations are mutually useful, for both relatives and staff
- The check list is useful to guide the conversation
- Relatives declining the offer of a call reported having received sufficient information during the admissions

## Challenges:

- In the beginning, few relatives said they wanted a call. We therefore changed from offering a call to informing about it
- We adjusted the time for the call from 4-6 to 6-8 weeks post bereavement, as relatives reported that 4-6 was too short time to settle
- We adjusted our written procedure accordingly

## Key points:

- Thorough preparations (see Process above)
- Scheduled time to make the call and document its contents (one hour)
- The nurse on call at the time of death or the nurse with the most contact with patient/family makes the call
- Common agreement among nurses that this is important, and regular evaluations

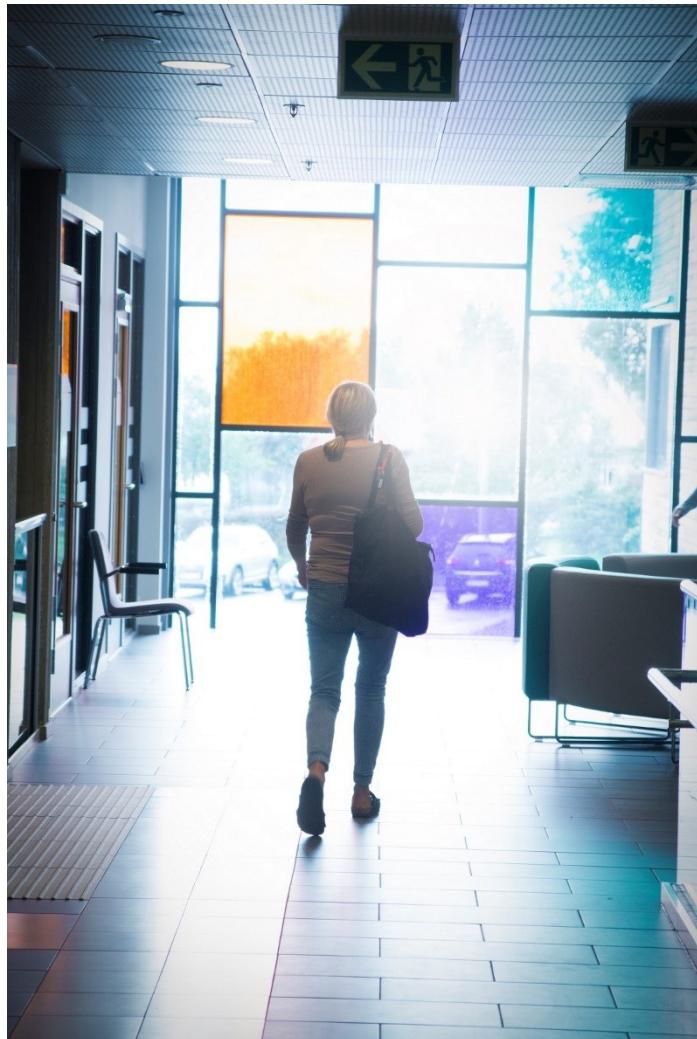
# Palliative care out-patient follow-up room on Tuesdays: hosting bereaved relatives

**Contact:** Physical Therapist MSc Juliana Nalin S Passarini, Hospital Estadual Sumaré (HES), Campinas, Brazil [junalin@hotmail.com](mailto:junalin@hotmail.com)

## Context and Driver:

We used the results of a post-bereavement survey in 7 European and South-American countries about care of dying cancer patients in hospital in order to improve the quality of care.

In our focus group, relatives reported that they missed follow-up from the hospital ward after the patient had died.



## Aims & Intended Outcomes:

- Ensure that all relatives of palliative care patients are offered a conversation in the patient's final days and as a follow-up during bereavement
- Offer a follow-up visit (optional)

## Process:

- Project information to staff (emails, staff meetings)
- Education and training
- Offer a follow-up to bereaved relatives

## Benefits:

- Relatives report that the conversations are useful, they feel cared for
- Many doubts that family members had about the care of their loved ones, were resolved

## Challenges:

- To reach everyone in need of a conversation
- Clear up any doubts that have arisen

## Key points:

- Effective and supportive communication and listening

# Babies photo memories

**Contact:** Physical Therapist MSc Juliana Nalin S Passarini, Hospital Estadual Sumaré (HES), Campinas, Brazil  
[junalin@hotmail.com](mailto:junalin@hotmail.com)

## Context and Driver:

The CODE project focused on the adult patient, but in our hospital, palliative care has also reached the pediatric and neonatal sections. The parents of terminally ill children ask for emotional and spiritual support. Some photos to record special moments may be taken.

## Aims & Intended Outcomes:

- To support parents of dying children
- To record memories



## Process:

- When we talk to the parents of terminally ill children, one of their fears is to forget the child's face. We arrange photo shoots and present the parents with photo books.



## Benefits:

- Support for grieving parents and siblings

## Challenges:

- To meet the parents' needs for support

## Key points:

- Be sensitive for the parents' wishes
- Sensitive and caring communication and approach
- A skilled photographer

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