

'Food should give pleasure and comfort
no matter the stage of life.'

Foreword by Maggie Beer

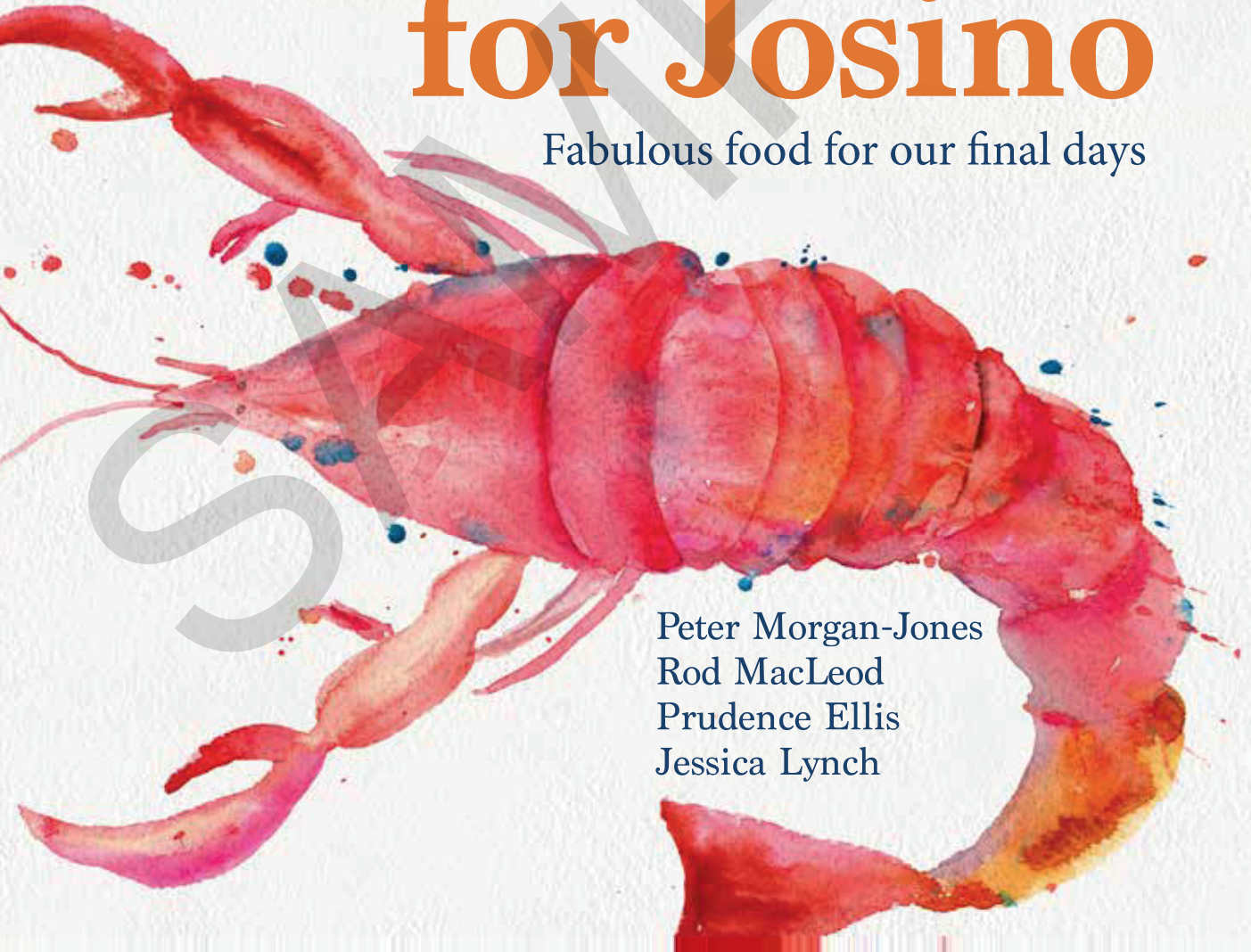


Lobster

for Josino

Fabulous food for our final days

Peter Morgan-Jones
Rod MacLeod
Prudence Ellis
Jessica Lynch



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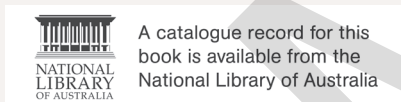
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The recipes contained in this book have been carefully tested to produce the desired food consistency and texture. However the authors cannot guarantee results due to a number of variable factors including cooking conditions, inputs varying across brands and products being subject to change over time. Accordingly, all care must be taken on each occasion when applying the recipes to verify that the consistency and texture of the food is appropriate and safe for its intended use.

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Introduction

For the love of food

Peter Morgan-Jones

Josino, a striking Portuguese man, worked as my second chef in the famous Bennelong Restaurant at the Sydney Opera House. Twenty years on from those days, having remained in touch, I received a phone call from his wife.

Josino was dying, she said, and had asked if I and another former colleague, Dave, would come to see him in palliative care at a Sydney hospital. We arrived during a rainy Tuesday lunchtime to find Josino in bed, looking very weak, although still wearing his distinctive, cheeky smile. We sat and reminisced about fun times working in the kitchens of the Opera House.

As we were laughing the nurse arrived with Josino's lunch. I could see his shoulders drop as he lifted the plastic lid that was keeping his hospital meal warm.

Josino declared the food looked and smelt awful and he complained that he wouldn't and couldn't possibly eat the meal offered. He was only managing small meals at this stage.

'All I ask is to be able to choose what I want to eat,' Josino said.

'Well, what do you feel like eating?' I asked.

He smiled that cheeky grin and said, 'Lobster Pete!'

We spoke to the nursing staff, suggesting we could buy a lobster from the nearby fish markets and prepare it for our friend. They deemed it inappropriate and would not agree. When I visited Josino again two days later he was in a coma. He never regained consciousness.



A new culinary direction

It was this experience, in part, that changed my culinary direction and inspired me to forge a new career working to improve the quality of food for people in need, especially those in aged care and people living with dementia and now, people facing their final days.

As Josino said on that rainy Tuesday, even prisoners on death row have the choice of a favourite ‘last meal’. Sadly, Josino was deprived that option in care, but his loss, I hope, will lead to others having a better experience.

For many people at the end of life, there is still huge enjoyment to be found in food and drink that they love and that is also appropriate for their condition. Many doctors now advocate for the ‘pleasure meal’ or seek to support the food requests of a person close to death. The risks can be discussed with loved ones and managed to accommodate a person’s (sometimes dying) wishes.

More than nourishment

Since the beginning of time, humans have instinctively known that offering food is a key part of caring for one another in sickness and in health, from the breast to the deathbed.

Food is not only important for nourishment, but also provides a great source of pleasure and comfort, not the least through the ritual of eating together, or in the sense of family that shared mealtimes can create.

Lobster for Josino has been written with the absolute belief that we should all be able to enjoy fabulous food, especially when faced with a life-limiting illness, even in our dying days—whether at home or in hospital.

Some simple steps to create a positive eating environment include:

- making opportunities for families and friends to eat together
- discussing patient’s wishes and needs regarding food and nourishing drinks
- access to food and drink 24/7 with a range of choices on offer
- reducing levels of worry and anxiety about food and appetite
- not being annoyed if the patient is unable to eat food when served
- ensuring adequate lighting and a comfortable seating position for eating
- making sure the environment is quiet and free from ‘institutionalised background noise’ if possible

- helping the patient relax before eating, perhaps through music, meditation or even a simple hand massage.

Why a cookbook for end of life?

We believe the benefits of enjoyable eating and drinking will often outweigh the associated risk burden for someone who is unwell.

And while there are cookbooks for virtually every other stage of life, few address what may be the most powerfully significant and challenging period of our lives, the very end.

That's why we have written *Lobster for Josino*—to build on the approach of our two previous (dementia-specific) cookbooks—*Don't give me eggs that bounce* and *It's all about the food, not the fork!* which filled gaps in resources for helping vulnerable people enjoy beautiful food.

In these earlier books, there are many recipes that are also suitable for people in a palliative stage in their life, including if they are experiencing swallowing difficulties or would benefit from smaller or modified meals.

Specific palliative care advice

It has been a privilege in *Lobster for Josino* to specifically focus on food for the end of life and to be joined by such a passionate group of authors including palliative care specialist Professor Rod MacLeod, dietitian Jessica Lynch and speech pathologist Prudence Ellis. You'll also find some excellent practical tips scattered through the book from occupational therapist Kate Needham.

Together we address issues such as:

- food, eating and changes to the palate
- sensory changes resulting from medications
- the importance of understanding the taste profile of the person in care
- approaching food on an individual basis
- common symptoms such as feeling nauseous due to food smells
- mouth care, swallowing, appetite and more.

Lobster for Josino also looks at options to improve the dining experience in palliative care if a person cannot communicate or even if they cannot eat anymore! This includes introducing sensory experiences to assist with mealtimes such as basal stimulation and also molecular air, liquid puree foods, foams and using thickeners.

About the recipes

Many recipes are ideal for trying at home and can be cooked and enjoyed by anyone, including carers and the person with a life-limiting illness. Some recipes will be especially useful for the advanced cook, palliative care hospitals, hospices and care homes—with ideas and techniques useful for supporting mealtimes when a person is receiving palliative care.

Commonly, the recipes in this book will include options for smaller sizes, suitable for lighter, more frequent meals. We are also mindful that sleeping and meal patterns may be altered towards the end of life and so rather than organising recipes around mealtimes such as breakfast or lunch, our sections include savoury, sweet, crunchy and soothing.

And don't overlook our comprehensive sections on nourishing drinks and super soups, as well as some creative approaches to enjoying an alcoholic beverage!

As I fondly remember my late friend Josino, I know he would be pleased that *Lobster for Josino* is all about finding ways to say yes to the very personal and meaningful food choices of a person who is dying, and we have his love of lobster to thank! Here's to you my friend.

Cheery.



Chapter 1

Food, care and the end of life

Rod MacLeod, palliative care specialist



‘If you don’t eat—you’ll die’ is a common thought for those caring for people near the end of life. Of course these people are already dying, but it doesn’t lessen the concern that many families and patients feel when food-related issues become an unwanted focus of attention and possibly anxiety.

Although this cookbook is full of beautiful recipes suitable for people near the end of life, we can’t ignore the reality that for many people at this stage, their desire for food can be much reduced or greatly changed.

These changes in food preference and eating habits can become a source of conflict. Families may feel helpless as they witness daily weakening and decline, so that strong emotions rooted in a sense of frustration and powerlessness may complicate an already tense situation.

Helping family and friends come to terms with their loved one eating less or very little is a key understanding. From this base, it will be easier to find creative ways for a person in their last days or with a life-limiting illness to enjoy the sights, smells and tastes of food—and the love in which it is shared.

Food and its purposes

The biological purpose of food, put simply, is ‘to provide the nutrients essential for life’. If this is so, then what is its purpose when people reach a phase in their life when much of what they are experiencing is deterioration and decline?

That’s when it is good to remember that nutritional sustenance is not the only purpose of food. Throughout life it is seen as a source of nurturing and of community—food and eating is a social imperative.

Every culture has rituals around the giving and receiving of food—it is often seen as an act of love or affection, an instinctive act of nurturing. At

the same time, across cultures and faiths there is a huge variance in the way the need for food is perceived. In one study that compares cultural approaches to feeding, all of the North American nurses said they would never force-feed a patient with advanced, incurable cancer who refused food but all of the Chinese nurses said they would feed such a patient¹.

A tip from our OT: As described in this book, attitudes, tastes and desire for food can be altered by the illness or treatment. But there are still many ways to be involved in food and meal rituals. If you enjoy cooking, you may be able to participate in aspects of cooking while sitting on a chair in the kitchen, or be involved in testing and smelling the food as it is cooked. Another option is having friends and family consume their meal with you at your favourite chair. This will keep you involved in the rituals shared at dinner, such as updates from family and friends.

A complex dilemma

Let's further unpack the often complex dilemma of eating and drinking for people near the end of life and their families. Some of the key issues include:

- reduced or changed appetite and rejection of food, while families continue to associate providing food and eating a good meal as an aspect of love and care
- eating less or very little, which in turn impacts other areas of wellbeing and care (see below)
- craving certain (favourite) foods, meals and drinks that staff and family may think are unsafe or they don't know how to provide in an appropriate way
- taste 'likes and dislikes' changing—which is hard for families to accept
- wanting to experience certain tastes and smells of food and drink but without consuming a large meal (or anything at all!).

Chapter 3

Swallowing difficulties in palliative care

Prudence Ellis, senior speech pathologist



Swallowing is one of our most basic reflexes—something to which we rarely give thought until it is unwittingly brought to our attention.

Have you ever felt something get stuck in your throat or go down the wrong way? Have you hurt your mouth as you eat, or experienced pain in your throat as food goes down? You suddenly notice how you are swallowing, paying attention so as to avoid any more damage. Consider how distressed you may feel when the swallowing process is disrupted, and how difficult it is to go about your activities while the discomfort remains. This may be a common experience for people approaching the end of life.

Swallowing difficulties may occur as a part of general weakness, changes in neural control of the swallow, or as a side effect of medications and/or dry mouth. This occurs in almost half of all people in palliative care.

The goal for speech pathology in palliative care is to accommodate (where possible) a person's desires for eating or drinking (if any), support carers and loved ones, and help achieve balance between a desire for safety and a need for comfort (which have in the past been incompatible). This might help reduce distress—both for the carer and the person receiving palliative care.

Swallowing safely

When a person is no longer able to swallow safely, it may result in food to 'going down the wrong way' (aspiration), placing them at risk of choking, pneumonia and further deterioration.

A speech pathologist strives to support families and people receiving palliative care to determine their wishes about food, and advise on safety (when appropriate). The role of the speech pathologist is not to strictly define what can or cannot be achieved, but to support those involved. We

may discuss the possibilities and offer our advice, but this must be balanced with the key priority of respecting the wishes of the person in palliative care.

Choice and quality of life

In palliative care, there is a particular emphasis on choice. At all times, it is the right of the person to make decisions about the care they receive. On some occasions, these wishes may contrast with those of the family. A person receiving palliative care may wish to eat and drink their favourite things, regardless of the risks involved, while the carer or family may want them to remain as safe as possible. Unfortunately, these desires may be mutually exclusive and cause contention. A speech pathologist can offer education and advice about what may or may not be safe, and call upon the health care team to assist the family and person in palliative care with decision-making.

The decision made will dictate the care of the patient—if everyone wishes to be as safe as possible, a speech pathologist may provide recommendations that are conservative. If someone chooses to accept the risks of aspiration, a speech pathologist may advise on oral care and strategies to do this as safely as possible.

In other settings, a speech pathologist may perform a series of assessments and therapies to assist with swallowing. For example, X-rays can inform a speech pathologist of the mechanics of a swallow (those features that cannot be seen at the bedside). In the palliative care setting, a bedside assessment by a trained speech pathologist is often sufficient to inform recommendations. Further tests may be unwarranted and cause unnecessary distress to the person, without changing the treatment suggestions.

Swallowing changes and complexity

A variety of changes may occur in a person's swallowing function. These may be as simple as dry mouth or changed oral secretions, delay in the swallowing reflex, and altered taste (to name a few). Or it may be a combination of some or all of these.

How we swallow

Before eating, we see the food or drink. We smell the food before it enters our mouth as well as when it is in our mouth. This forms part of our taste. We feel the texture of the food in our mouths, and move it around to capture

Recipes



Our recipes are organised around tastes and textures so rather than breakfast and dinner, you'll find sections such as sweet, savoury, crunch and soothe, mists—and even flavoured air!

- Ⓡ Regular diet, no restrictions
- Ⓢ Soft
- ⓂⓂ Minced-moist
- ⓈⓅ Smooth pureed
- Ⓣ Thin fluids, no restrictions
- ⓉⓂ1 Mildly thick
- ⓉⓂ2 Moderately thick
- ⓉⓂ3 Extremely thick
- ⓃⓂ Nil by mouth



Savoury

Whether it's a meal or just a mouthful, these flavoursome recipes are the definition of more-ish!



Asparagus and pea risotto

Serves 2-4
Prep 15 mins
Cook 20 mins

500 g fresh seasonal asparagus
50 g butter
½ small onion finely diced
¾ cup carnaroli Risotto rice
½ glass chardonnay
100 ml vegetable stock
½ cup defrosted green peas
2 tbsp freshly grated
parmesan cheese
2 tsp sea salt flakes
1 tsp ground white pepper

R S T Th1 Th2 Th3

If modified MM SP

Cut 2-3 cm tips off the asparagus and set aside. Cut remaining asparagus into 4 cm lengths and cook through in salted water. Blend a little of the liquid with the cooked asparagus and pass through a sieve to remove any fibres. Add the puree to the remaining cooking liquor (about 1 cup). This is the asparagus stock.

Melt the butter in a saucepan and add the onion and let it begin to soften until transparent. Stir in the rice with a wooden spoon and let it absorb all the flavour from the onion and butter. Add the asparagus tips and then the wine, stirring it all together gently.

Turn up the heat until the wine has evaporated, then slowly ladle in the boiling asparagus stock—when the rice absorbs the liquid add another ladle. Repeat until the rice is tender. Use other stock if you run out of the asparagus stock. Finally, add the defrosted peas.

This needs constant care—stirring and adjusting. When cooked add about 1 tbsp butter as well as parmesan and salt and pepper to taste.

Serve immediately with (extra) good quality Italian grated parmesan.

Tips: ~ Cooked chicken breast, diced with mushrooms is a more substantial meal for a different taste.
~ Any left-over risotto can be made into patties, crumbed and used as a side for a main course.
~ For a minced-moist or smooth puree dish, simply puree the risotto until smooth (allow small lumps for minced-moist diet) and instead of whole peas, add a pea puree to serve.



If you're the kind of person who wants every meal to be dessert, this section's for you (even if it's just a mouthful or two)!



Apple gingerbread

Serves 1 loaf
Prep 15 mins
Cook 40 mins

3 peeled and sliced
granny smith apples
3 tbsp caster sugar
3 tbsp brown sugar
3 tbsp golden syrup
1 tbsp maple syrup
1/3 cup butter
6 tbsp self-raising flour
1 tsp baking powder
1 free range egg
2 tsp ground ginger
1/2 tsp ground cloves

Cinnamon icing

6 tbsp icing sugar
3 tbsp hot water
1 tsp ground cinnamon
Zest of 1 lemon

Add the sliced apples and caster sugar into a small saucepan with 3 tbsp water and bring to simmer. Cover and cook until soft.

Mash up the apple and allow to cool, place the liquid in a pan with the brown sugar and the syrups, allow sugar to dissolve on a low heat and then to cool.

Sift the flour and baking powder into a clean bowl. Beat the egg and add to the syrup and butter, beating very well. Preheat oven to 180°C. Add the cloves and ginger to the egg syrup mix and then gradually add the flour until a batter is formed, fold in the cooked apple.

Pour into a well-greased bread tin and bake in preheated oven for 30-40 mins on the middle shelf.

Next rub the icing sugar through a sieve and add the cinnamon and lemon zest, stir in the moderately hot water and mix well. Remove the gingerbread from the tin and pour over the lemon cinnamon icing. For a smooth pureed diet, remove the outer crusts and serve with custard. For all other diets, pour over the lemon cinnamon icing before serving.



Tips: ~ This recipe is also delicious with cooked rhubarb or cooked pears.





Beverages

Tasty, refreshing drinks—including some clever variations on favourites from the bar, so no one need miss out.

Avocado, lime and cashew smoothie

Serves 2

Prep 2 mins

1 avocado ripe, peeled
and stone removed
150 ml almond milk
2 tbsp unsalted cashew nuts
1 tbsp skim milk powder
1 tsp coconut oil
Handful of ice cubes

(R) (S) (MM) (SP) (T)

If modified (Th1) (Th2) (Th3)

Place all ingredients in a blender and blend until smooth. Pass through a sieve if required to ensure a smooth consistency.

Tip: ~ Thicken this smoothie for those on thickened fluids using a commercial thickener.

Black grape, spinach and blueberry smoothie

Serves 2

Prep 5 mins

1 apple, peeled, cored and
roughly chopped
1 cup frozen blueberries
1 cup frozen seedless
black grapes
2 handfuls of baby spinach

(R) (S) (T)

If modified (MM) (SP) (Th1) (Th2) (Th3)

Place all ingredients in blender and blend until smooth. Pass through a sieve if a smooth consistency is required.

Tip: ~ This smoothie could be adapted for those requiring thickened fluids. Outcomes may vary, so use a commercial thickener and compare to your pre-thickened fluids to ensure the correct consistency is achieved.

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