



# UPBEAT

The Newsletter for People with Early Onset Parkinson's  
 Understanding Parkinson's by Belief in Education, Attitude and Treatment



## Finding flavour

*When Lance contacted Parkinson's New Zealand about his 'food experiments' we thought others might be interested in how he had gone about finding what foods he could still taste.*

Lance was diagnosed with Parkinson's when he was 48. During the consultation with the neurologist who was diagnosing him, three vials were passed under his nose. He couldn't detect an aroma from any of them and later found out they were peppermint, eucalyptus and Jeyes fluid.

A self confessed 'foodie' the effect of losing his sense of smell was that food also lost its flavour, or that flavour was changed as aroma determines most of what we taste. So he set about experimenting with what food he could taste.

"For me, Marmite became a salty taste, and oranges an acid taste. Shrimp no longer tasted of anything. Now I knew why for many years any Cabernet Sauvignon wine tasted to me like vinegar." Lance said.

"Food was, and still is, a major part of my life. My earliest memories involve the kitchen and baking. Recent winters had been warmed by doing night classes in cooking, my friends were asking me why I was not going to try out for Masterchef. I went to a whisky club where a glass is passed to you with the minimum expectation that the region of Scotland is identified. Rather than lose this all I decided to look at cooking with what taste I had left."

Lance tried searching on Google for information on eating with a diminished sense of smell and found little useful information. There seemed to be no books or literary articles to draw on and diet guides seemed to indicate there was no need to make changes. "But I felt a real need to change my diet. With diminished taste sensations the eating experience needs to be enhanced if I'm going to enjoy it. If I could no longer taste food then I needed to find other ways to enjoy it. So I started out by noting which foods I could taste and which I couldn't."

"The mind is a very adaptable thing and can be trained" Lance says. He has found that steak tastes more 'beefier' eaten on its own than if used in a casserole as his mind remembers what the steak tasted like. He finds that given the right cues food can taste better using his memory to enhance the taste.



Lance Risk

Here are Lance's suggestions on making food more enjoyable.

### Colour

Food isn't all about taste. Considering improving the look of food by using colour. Lance considers both the colour of the dish the food will be on, and the food itself when looking to create a colourful meal. For example a salad looks more interesting if it has a mix of coloured leaves, rather than just one sort of lettuce.

### Texture

Adding texture to a dish can also make it more interesting. Bean sprouts are a good way to add texture to a salad, they can also be stirred into a casserole as it is served so they heat through but don't cook. This provides a depth of texture to the casserole.

Rice is also Lance's favourite over potatoes as for him the taste is better and rice provides more texture. Using different types of rice, e.g. basmati, jasmine and glutinous adds to variety.

Whole grain or seeded bread or artisan bread like focaccia or sour dough may taste better. They also have more texture than standard white bread.

### Try food both raw and cooked

Lance found that fruit and vegetables may have more taste depending on if they are raw or cooked. He found carrots once cooked lost their natural sweetness. He also found that apples eaten raw had little or not taste but that apple sauce was nice with pork.

### Don't mix food up

In a casserole, all the flavours blend together and Lance found the meal became "20 forks full of the same thing". By putting the vegetables on the side, not mixing them in to the casserole, the meal becomes more varied and interesting to eat.

### Spices and condiments

Condiments like mustard and sauces are still enjoyable although the salt or vinegar component may be more pronounced. Lance finds that both Indian and Thai curry flavours are still very enjoyable. Thai flavours are very taste bud oriented. He recommends that even if you don't like a hot curry, a small amount in a casserole may improve the flavour.

### Jams and spreads

Try out different flavours to see what you can still taste. Lance finds most jams taste the same, but blackcurrant has a better taste range. Peanut butter and thinly spread Marmite are still enjoyable.

### Coffee and Tea

The impact of fancy tea like Earl Grey is lost on Lance so he sticks to 'gumboot' tea. However he finds that properly brewed coffee is still enjoyable even if the flavour isn't as complex as it used to be. Try different blends of freshly ground coffee to see what suits you best.

*Parkinson's New Zealand would like to thank Lance Risk formerly of Christchurch and now living in Melbourne for this article*

Lance keeps a track of the food he tries and how well he can taste it on a table. A sample of this is shown below. He uses this table when looking at recipes and deciding what to cook.

Vegetables		Fruit		Meat		Herbs & Spice	
Potato	0	Orange	2	Beef	5	Ginger	10
Tomato	5	Banana	5	Pork	5	Garlic	5
Celery	7	Apple	0	Salmon	2	Coriander	5

## 2014 UPBEAT Weekend

The date for the 2014 UPBEAT weekend is Friday 22 to Sunday 24 August. Hosted by the Hawke's Bay Division, the event will be held at the Kennedy Park Resort in Napier.

If you haven't been to an UPBEAT weekend before you should consider coming to this one. If you have been before, we would love to see you again.

UPBEAT is Parkinson's New Zealand's special interest group for people with early onset Parkinson's. The UPBEAT weekend is open to people diagnosed before the age of 60 who are currently under 65 years of age. This is an opportunity to meet new people who are also living with Parkinson's, learn from each other, and find out more about managing this condition.

In the feedback we have received from past weekends many people have said being around other people who 'understood' is a highlight of the weekend. "Not having to explain about Parkinson's or what is going on with me". Partners are also encouraged to attend the weekend. One member told us "it was also great for my wife to be able to talk to other partners who knew what she was experiencing".

Parkinson's New Zealand are now in the process of putting together the programme for the

weekend and we need to know what information you want.

### Tell us what you want on the 2014 UPBEAT weekend programme

UPBEAT is your weekend, so we want to know what topics for speakers, workshop programmes and other information interests you. Please give us a call or email [upbeat@parkinsons.org.nz](mailto:upbeat@parkinsons.org.nz) to tell us what you would like to see on the programme.

### Do you have a topic to share?

A new initiative for the 2014 UPBEAT weekend is member designed content. We are looking for people to give us expressions of interest of topics they can present on.

Presentations can be on anything related to Parkinson's. You might have found a great type of exercise that helps you, or want to share web resources you regularly access. Your partner might have suggestions on things they have found help them or the person they care for - you might even want to do a presentation with another person.

To let us know a topic you would like covered at the weekend, would be prepared to present on, or for more information, please email [UPBEAT@parkinsons.org.nz](mailto:UPBEAT@parkinsons.org.nz)

## Connect with others affected by Parkinson's

► Join today!



HealthUnlocked

Parkinson's New Zealand's online community on HealthUnlocked is a place where members can ask questions, talk to each other or share their ideas on living with Parkinson's. You can join this community by using the link on the front page of our website [parkinsons.org.nz](http://parkinsons.org.nz)

UPBEAT is a special interest group of Parkinson's New Zealand

**UPBEAT Mission Statement:** To improve the quality of life of people with the early onset of Parkinson's and their families by sharing information, experiences and strategies through interpersonal communication and support, until there is a cure.

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## Web Resources



### Parkinson's New Zealand's You Tube Channel

Have you looked at our You Tube Channel lately? At the World Parkinson Congress we videoed short (3–5 minute) presentations and interviews with people who spoke at the Congress. Here are just a few of the topics available.

#### Are you demoralised or depressed?

Janis Miyasaki from the University of Toronto discusses the difference between being depressed and being demoralised and how the treatment of these conditions differ.



#### Accurately diagnosing Parkinson's

Roger Barker from Cambridge University talks about advances in diagnosing Parkinson's and why this is so important both for treatment and research.



#### Exercise themes from the WPC

Terry Ellis from Boston University explains the importance of exercise as a preventative therapy for Parkinson's.



#### Flying solo, living alone with Parkinson's

Ryan Tripp has lived with Parkinson's for 17 years. He discusses living alone with Parkinson's, asking and accepting help to enable you to do this and other strategies he uses.



#### Advice for people with Parkinson's with children

This under-researched topic was the subject of a number of workshops at the WPC. Parkinsons' NZ recorded three interviews with the presenters who give their advice on being a parent when you or your partner has Parkinson's.



#### Service dogs for people with Parkinson's

Carolyn Weaver and Renee Le Verrier introduce their Parkinson's service dogs and demonstrate the sort of help they can provide



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