



Touchlines

The Newsletter of Cancer Support France — Association N° W163000037

*Patron: Prof. Alain Daban: parrainée par le Professeur Alain Daban, professeur émérite de la faculté de médecine de Poitiers" et "président d'honneur du Réseau Onco-Poitou-Charentes
La président d'honneur :Mme Linda Shepherd*

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Linda Shepherd
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Dear Readers,
With the of triggering Article 50 many of you will be experiencing uncertainty and anxiety regarding our futures in France ,especially how it will affect reciprocal health care arrangements with the UK amongst other issues.
However Cancer Support France and all its regional groups will continue its great work supporting members and friends across France. There will be many fund raising and awareness events to look forward to and hopefully we will all be able to see more clearly how the immediate future pans out.
If any of you would like to send me articles or "good reads" that readers may find of interest please send them to csftouchlines@gmail.com

Editor : Peta Hamilton .



"It was with great sadness that I wrote to all the CSF Presidents to tell them of the death of Linda on Thursday 23rd March.

Linda's vision and determination, her tireless support of all the associations and the example of how she lived her own life with cancer is an inspiration to us all. Even after she had retired from CSF, it remained uppermost in her thoughts and only the previous week she had asked me to pass on "(my) love to National".

Her wisdom and kindness, her ever ready ear to listen, her dedication and commitment will be greatly missed.

Our thoughts are with Andy and Linda's family and friends at this time, in the hope that her achievements and the CSF legacy she leaves will bring some comfort."

Penelope Parkinson
CSF (National) President

CSF NATIONAL NEWS
CSF (National) AGM
15th March 2017

As there were no Agenda items necessitating debate, it was decided to hold a low-key AGM this year. This took place in the informal surroundings of the Rajpoot Restaurant near Toulouse. A review of the past year and goals for the coming year were discussed, as well as the approval of the accounts and budget. Once the legal requirements had been concluded (against the background of Indian music!), an excellent and convivial lunch was enjoyed by the 12 attendees from 7 associations.

The representatives for the National Conseil for 2016-2017 are:

Alpes-Maritime	Angela Anderson (deputy Charlotte Leahy-Taylor)
Bordeaux	Marisa Raymond
Charente-Maritime	Dick Smith
Charente Plus	Vanessa Whyte
Dordogne Est & Lot	Pat Lockett
Dordogne Riberac	Michael Joyce
Dordogne Sud	Bob Kennedy
Gascony	Jayne Ray
Languedoc	Graham Luck
Lot et Garonne	Cindy Sheppard
Nord	to be appointed
Paris & Île-de-France	Sarah Valinsky
Provence Gard	Tim Forster
Sud de France	Penelope Parkinson
Vienne	Jacque Kelly

Penny was re-elected President for the coming year with Stephen Hartley continuing as Treasurer. Pat Lockett remains as the National Training Co-ordinator. Although this ex-officio appointment will need to be ratified at the first National Conseil meeting and subject to that, Steve Nicklen has been appointed Public Relations Co-ordinator.

Penny concluded the AGM by saying ".....a big thank you to all our members across France for their support whatever form that takes, from our ALs to a member who simply pays their subs. They are all equally valuable and without them CSF could not have developed into the national association that we have today."

Penny Parkinson

CSF (National) President

CSF joins Alvarum for donations and sponsorship

With the Canal Cycle Ride coming up in June, the National Conseil had a look at finding easy methods to raise funds through donations on line for those of us in France. CSF has now joined **Alvarum**, a European website which operates in the same way as Just Giving and which offers English as well as French. Once a charity registers with them, a number of options become available.

First, a person wishing to make a donation types CSF into the search box to find the correct page. There is a donation button in the usual way and the instructions are straightforward.

Secondly, it is possible to set up a personal donation page linked directly to CSF. It is quite easy - you click on the home page to indicate that you wish to raise funds for an association and indicate the association name. That takes you to a new page asking if you are raising funds for an event or an occasion. If, for example, you wish to seek sponsorship for the Cycle Ride, you select 'event', 'continue' and type 'Cycle for Life' in the next search box. You can then set up and personalise your page with donations going directly to CSF and a tax receipt being issued to your donors.

Do have a look at the website, you will see pages are already linked to CSF. Two brave chaps are running the Paris marathon!

CLIENT STORIES—This is a new occasional feature where CSF members bravely and honestly share their “real-life” experiences with and around cancer.



Nick and Laurent’s story

Although, by early 2014, I was in remission following treatment for lower bowel cancer that had started in March 2012, my partner Laurent and I were still deeply affected by the stress and trauma of my illness. I felt as though I was in a bubble that isolated me from the rest of the world, and was very much aware that the end of my treatment did not signify the end of my journey as a cancer patient, nor of Laurent’s as my main carer. It was at this time that we saw a CSF-Languedoc poster at my gastroenterology clinic and decided to get in touch.

We were immediately encouraged by the warmth, moral support and, most importantly, the understanding we received from everyone we came into contact with at CSF, be they Active Listeners, other volunteers, or those who had also experienced living with cancer. After just one conversation with my Active Listener I lost all sense of isolation. It was like stepping from a fog into a clear day, where everything started to seem normal again.

To be able to talk so frankly and openly about the emotions and concerns we had felt during the treatment and since it ended, was a very positive experience, allowing us to quantify and look at what we had been through much more objectively. When you know the people you are talking to don’t just understand, but really care about how you are feeling, it makes a huge difference to your morale. It was like being among family, but without the awkwardness and difficulties that can often arise when talking about cancer with those that are closest to you.

Throughout my diagnosis and treatment, we had also found the medical support provided by the French healthcare system to be second to none. In particular, accessibility to medical personnel was outstanding: we were regularly reminded that we could contact a dedicated nurse at the radiotherapy clinic if either of us had any questions or concerns. But it’s not just the medical treatment that gets you through; it’s the emotional and practical support that runs in parallel with that – and far beyond. This is where CSF is so special. The care and understanding we have received from our Active Listeners and the other friends we have made through regular attendance at Drop-In days (which we try never to miss and always enjoy) has been incredible. Neither of us can imagine how things would have been if we hadn’t discovered CSF.

In November 2015, Laurent learned a lot more about the breadth of the support that CSF give when he attended an Active Listener training course. He says that it is this vast range of support and services that make CSF so unique.



 **Calibre audio library**
the freedom to read

For the blind and partially-sited, don’t forget listening books can be sent to France via Calibre Audio Library:
www.calibre.org.uk



DOCTOR'S NOTES

The regular feature in Touchlines where our resident General Practitioner, Dr Sarah Cousins will be writing on a variety of topics around the subject of cancer, which she hopes that our readers will find interesting and helpful.
Editor

Dr Sarah Cousins is a GP in the West Midlands with an interest in cancer care and palliative care. Within her practice she is the cancer and palliative care lead and has previously worked in various hospitals including at a chemotherapy unit. She lives in Worcestershire with her husband.

Prostate cancer

Prostate cancer is the most common cancer in men in Europe and most commonly affects those over 65. The prostate is a gland just below the bladder in men which has a role in making fluid for ejaculation.

Symptoms

Many cancers are slow growing and may cause no symptoms

Many men, as they get older, develop a benign (non-cancerous) enlargement of the prostate and this can cause the same symptoms

Urinary tract symptoms are seen

Poor stream- the flow is weaker and slower

Hesitancy- takes time to start the flow

Dribbling- small amounts leak out after you think you have finished

Frequency- going more often

Urgency- having to rush to go

Poor emptying- feel as if not fully emptied your bladder

Occasionally pain or blood in urine or ejaculate may be seen

Cancer can spread to other parts of the body, especially the bones causing pain

Diagnosis

The doctor will examine the prostate through the back passage. This can find benign enlargement or abnormal areas. The examination involves lying on your side on a couch and only lasts a few moments. It may be uncomfortable but shouldn't be painful. You may feel embarrassed, but please remember that doctors are used to examining this area and will try to put you at your ease. A chaperone can be arranged if you would like this.

PSA (*prostate specific antigen*) is a blood test that can be raised in cancer however a slightly high level can also be seen in benign prostate conditions

Biopsy involves taking samples of the prostate gland via the back passage which are then examined under a microscope. This is performed in the hospital using local anaesthetic.

Severity

Prostate cancer can be very slow growing or more aggressive. To assess this the PSA level, any spread of the cancer away from the cancer (shown on CT scans or bone scans) and the results of the biopsy samples are used

Treatment

Some men will have 'active surveillance' treatment if the cancer is early and slow growing. The PSA and the size and feel of the prostate are regularly checked. This may especially be used for older men who are unlikely to get symptoms from their cancer.

Surgery to remove the prostate if the cancer has not spread. Generally men need to be fairly fit for this surgery and it can cause problems such as incontinence and erection difficulties

Radiotherapy either external or internal may be used more commonly for men who are not fit enough for surgery

Hormone treatments do not aim to cure the cancer but slow the growth. They work to block the effect of testosterone on the cancer.

Chemotherapy or radiotherapy may be used for advanced cancer to slow down growth or to shrink or reduce symptoms from cancer that has spread

Screening

This is a controversial area. A high PSA may suggest cancer, but there are other cases. If a PSA is raised it often leads to more invasive tests such as biopsies, and a cancer that was never going to cause problems could be found causing anxiety and possibly unnecessary treatment with side effects.

It would be sensible to discuss PSA testing and its possible implications with your doctor, and certainly to report any urinary symptoms.

The information contained in this article is for information only and is not intended to replace seeking advice from your own doctor.

This will be Dr Cousins last article for Touchlines for a few months, as she is expecting her first baby very soon. We send Sarah and Matt all our best wishes and look forward to seeing photographs of her and the new baby.

CSF Charente-Plus—submitted by Mo Woolmer



We are delighted to inform our associates that Grace & Aimee at Equilibre Naturellement in *Rochechouart* kindly organised and ran a raffle to which they donated all the magnificent prizes, donating all funds to Cancer Support France - Charente Plus.

Grace presented our President Vanessa Whyte with a cheque for €200.00 at their VIP Soiree.

CSF Gascony –submitted by Jackie Clarke

It is the beginning of what will be a busy year for CSF Gascony.

Our first project is a Wellbeing day for our clients on the 28th March. We will be offering hairdressing, Reiki, Bowen Therapy and breathing, relaxation and gentle Yoga. This is a great way to give our clients a day/half day of relaxation and pampering.

The big news is the new project at the *Oncopole and Rangeuil Hospitals in Toulouse*. Our proposal is to have a presence in both these hospitals, with the possibilities of a phone in and physical presence and a beep system which could call upon volunteers when an English speaking patient is in need.

It is in the early stages of planning with the thought of certainly 4 times a year, but if possible, depending on the number of volunteers, once a month. The project is in association with CSF Sud France. It is also a great opportunity to mix with other associations working at the hospitals.

If this project works it will be a great template for other major hospitals around France.

We are holding our AGM on 19th April and very much looking forward to hearing from our members new ideas for fund raising and raising awareness.

Jackie Clarke
CSF Gascony



What is Lynch syndrome?

Lynch syndrome is an inherited condition that increases your risk of colon cancer and other cancers. Lynch syndrome has historically been known as hereditary nonpolyposis colorectal cancer (HNPCC). A number of inherited syndromes can increase your risk of colon cancer, but Lynch syndrome is the most common. Doctors estimate that about 3 out of every 100 colon cancers are caused by Lynch syndrome. Families that have Lynch syndrome usually have more cases of colon cancer than would typically be expected. Lynch syndrome also causes colon cancer to occur at an earlier age than it might in the general population.

For more information see <http://www.ihavelynchsyndrome.org/>

New President for Dordogne Est & Lot

At the AGM in January President Julia Hall stepped down and a new President, Heather Moorhead was elected. Julia has been president since July 2012 and under her guidance CSF Dordogne Est & Lot has gone from strength to strength. Highlights of her tenure include the formation of our own training team for Active Listeners and ensuring that this training is ongoing. She has ensured that fund raising has been consistent and maintained, and this association now stands in a very healthy position.



Outgoing President Julia Hall



new President Heather Moorhead

In the early days, with the help of her husband, a very successful Golf Day and Dinner was organised at *Souillac* with captain and players from C A *Brive*. This was a joint venture with the Golf Club and raised around €4,000 for our association. There have been many others over the years, including Marche de Noels and our own Activity for Life 2016, a 100 km canoe and cycle ride which raised €2361.86 by her husband Keith.

Julia has also been instrumental in establishing and maintaining contact with *La Ligue Contre Le Cancer* and has supported volunteers from CSF to help run their drop-in centre in Gourdon. Julia will continue to be involved with the association as an AL, Liaison Officer to *La Ligue* and as part of the National Response Team for the email helpline from the National website.

Julia is handing on the position to a very safe pair of hands. Heather brings a wealth of experience to the association as she has been Vice President of Dordogne Est & Lot in the past as well as Client Co-Ordinator for three years. In addition, in her "previous" life in England she was not only a head teacher for 21 years but also an Ofsted Inspector for 10 years. We are delighted that she has accepted this new and challenging role and are looking forward to the future

CSF Dordogne Est & Lot 10th Birthday Event

We started our Tenth Birthday celebrations on Saturday March 4th at the *Foyer Rural in Thédillac* with an evening event featuring: Rag Mama Rag; Neil Innes; The Hartstring Folk Duo; Jean Marie Redon & Sharon Lombardi; Sally Ann Harby and Mick Bass.



A very Big Thank You to all who came along to support us and enjoy the evening.

Thank you also to our organising team and all their helpers who worked extremely hard to provide very tasty chilli and a variety of delicious desserts.

The Team had decorated the Foyer and with 150 plus people, who responded so appreciatively to the wonderful music, a lovely atmosphere was created.

As you will appreciate with an event of this size it takes time to finalise the amount raised and we will announce the final sum raised as soon as possible.

A wonderful start to our Birthday Year.

Heather Moorhead: President

Client support update

It's been a busy time for the CSF-Languedoc client support team. We are currently supporting over 50 clients. This includes the extensive support involved when a client is first taken on: we are finding that more people are contacting us earlier in their diagnosis when they often have a lot of medical appointments. Our active listeners are now working in teams, which makes for a better use of resources and means it's rare for a client to have only one AL. Team working also means that professional levels of communication and report-writing are required, and this will be a focus for AL on-going training this year.

Drop-In

Despite the winter weather, we welcomed between 40 and 50 visitors at our first two Drop-In days at *Hameau Montplaisir* this year, including CSF National President, Penny Parkinson, who stopped by in January. Drop-In continues to be a highlight in the CSF-Languedoc calendar and our thanks go to the many volunteers who give their time to provide craft activities and complementary therapies every month. A very big thank you also goes to restaurant La Maison for supplying lunches at Drop-In and to our hardworking and super-efficient team of kitchen helpers and servers.



Drop-In day at Hameau Montplaisir.

2017 AGM

Our AGM, held in January, saw the outgoing bureau of Tony Orsman (Treasurer), Jenny Guest (Secretary) and Graham Luck (President) re-elected for a second term. The opportunity has also been taken to re-arrange the association's 'engine room', with Cat Hartley focusing on client support while Karen Powell takes over the lead trainer role.

CSF-Languedoc featured in SecondLife magazine

CSF-Languedoc was recently featured in an article in SecondLife magazine edited by Étincelle, a French association supporting women affected by cancer and their close ones.

La Montpellier Reine Fun Run - 18 June 2017

La Montpellier Reine, organised annually by the main cancer treatment hospitals in Montpellier, raises awareness of breast cancer and the importance of screening. In 2016 over 8,000 people took part in this 4.5km fun run/walk around the city's historic centre. For the second year, CSF-Languedoc is entering a team and we'd love members from neighbouring associations to join us. No sponsorship required; donations are discretionary and any funds received will benefit organisations involved in the fight against breast cancer.

If you'd like to find out more, visit <http://www.montpellier-reine.org/> or contact Jenny Guest at jenny.csflanguedoc@gmail.com by 18th May to register for the team.



The CSF-Languedoc team at last year's Montpellier Reine fun run.

Open Meeting Carcassonne:

As well as some spectacular floral displays and a plethora of nesting birds, spring has brought to the CSF Sud de France region a time of reflection. In particular we have been discussing how we may best share Best Practice with other regions to improve what is on offer to our clients, support groups, and group activities in general. As CSF grows, change is inevitable and reviewing what we do, with a view to evolving, seems to be a necessary and worthwhile activity for us all and the exchanging of ideas and best practice with each other should be of benefit to us all.

One particular challenge for Sud de France is that our region covers a vast, largely rural area, and both our clients and our volunteers are geographically very widespread. It would be of particular relevance to us to share with other groups in a similar position how this affects our activity.

As a first step in this direction we are holding an open meeting where we are hoping members, including those who are not currently volunteers, will attend, with new ideas and, hopefully, offers of expertise, experience and a willingness to become more involved in our activities. More details on what happened at the meeting in the next edition

Domaine Gayda

A Soirée du Charité was held on the 4th March at *Domaine Gayda in Brugairolles* in the Aude. This annual event to raise money for cancer charities is organised by Zoe Moore, and this year “CSF - Sud de France” and “*La Ligue contre le cancer*” will be the beneficiaries. Some 75 participants, including some members of CSF, enjoyed a lively evening animated by Amar Bal, and enjoyed excellent food and wine provided by *Domaine Gayda*.



October Rose

The balloon goes up: *La Ligue contre le Cancer Tarn* quite literally goes to town during October Rose month, spreading its fuschia pink umbrellas in all the major towns in the department. And they generously give the CSF Sud Tarn association space on their stands, thus giving us a chance to spread the CSF word all over the region. Throughout the month members could be found in *Carmaux, Cordes, Gaillac, Albi, Lavaur and Mazamet*. Pictured are CSF Sud Tarn members Denise Copley and Peter Waldekker at Mazamet just before the balloons went up.



Book Exchange Laroque

Our monthly book exchange at Cafe des Artistes produced a steady flow of visitors in the spring sunshine.



Coffee morning for Cancer Support France hosted by Beverly Clarke

Beverly Clarke of *Availles-Limouzine* opened her home and garden to host what can only be described as a very successful Coffee Morning. Cakes were not only made by Beverly, but also donated by those who attended the event. The cakes were sold and coffee served throughout the event, with over 60 people attending. A grand total of €400 was raised with half of the takings being donated directly to CSF, Vienne.

Books were donated for sale and were sold during the event and Kathryn Flight volunteered her services offering massages for donations. Beverly amassed a feast of cakes ranging from chocolate brownies and flapjacks to exotic sounding (and tasting) beetroot and chocolate or courgette and lemon cakes.

The atmosphere was fun and full of excitement as well as delicious cakes. People were overheard commenting on the “absolutely delicious and huge slice of coffee walnut cake”, whilst others thoroughly enjoyed the lemon drizzle cake and the brownies and the flapjacks.

Cancer Support France, Vienne would like to thank Beverly and everyone who participated in the Coffee Morning for their kind and generous contributions, even if it did involve buying back the cake you had donated. *If you would like to find out more about hosting a Coffee Morning, or any other event in aid of Cancer Support France – Vienne, please contact vienne-president@cancersupportfrance.org for more information, we look forward to hearing from you!*

Trio stitch 45 heart-shaped cushions to help bring comfort to breast cancer Patients

Three friends have clubbed together to bring comfort to breast cancer patients. *Millac* friends Anne-Marie Oliver and Alvina Farrow and Alvina’s mum Chris Johns joined forces in a scheme crafting cushions which help relieve the pain of mastectomy scars.

They were given the pattern from Cancer Support France-Vienne and set about getting material donated and provided the stuffing themselves.

The Heart Cushions are soft and supportive which have a practical use to cushion the surgical area during healing and to support arms affected by lymphoedema.

The trio have cut, stitched and stuffed their way to creating 45 cushions to date.

Alvina Farrow said “We want to encourage people not to be shy and if they need one, or know someone who needs one, to get in touch.”

The heart-shaped cushion is either tied under the arm or placed under a seatbelt to prevent pressure on a mastectomy scar.

We have included the pattern on this website if you or your friends would like to produce these cushions or have material or stuffing you would be willing to donate. Anne-Marie said “The cushion is a very simple idea, that’s the beauty of it, and it works. Our aim is, when we have a big supply, to go around we will pass them to Cancer Support France, Vienne to donate to the hospitals and those in need.”

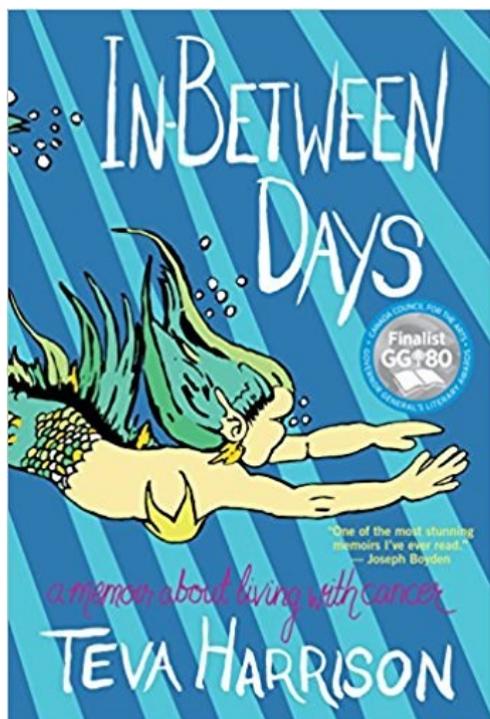
As well as seeking people who need the pillows, they are also appealing for donations of material, ribbon and more people to help make the cushions.

Anyone who is interested in finding out more or helping can contact vienne-president@cancersupportfrance.org For further information where to donate fabric, stuffing etc., the pattern and where to collect a cushion from.

THE BOOK CORNER

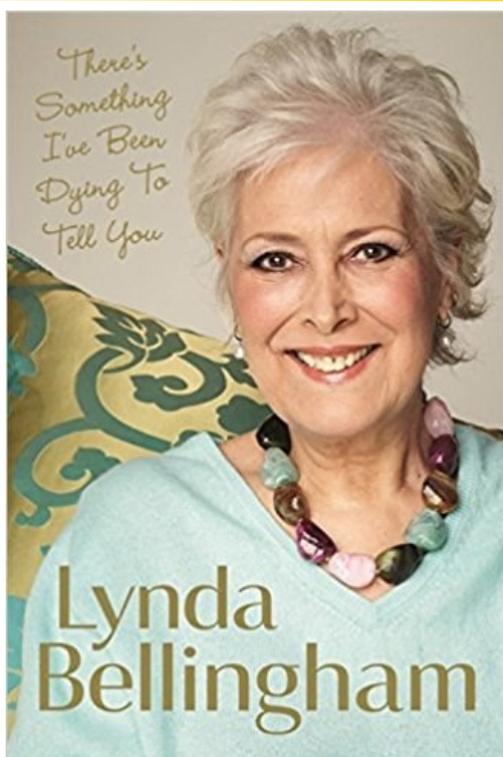


The purpose of the Book Corner feature is to identify books that could be supportive to those affected by cancer. It is not intended as a review and in no way constitutes any endorsement by CSF. Most books are available on Amazon.co.uk.



Teva Harrison is a writer and graphic artist. Her graphic series on living with cancer was published in *The Walrus*, and she has commented on CBC Radio and in the *Globe and Mail* about her experience. Numerous health organizations have invited her to speak publicly on behalf of the metastatic cancer community. She lives in Toronto.

Teva Harrison was diagnosed with metastatic breast cancer at the age of 37. In this brilliant and inspiring graphic memoir, she documents through comic illustration and short personal essays what it means to live with the disease. Ultimately redemptive and uplifting, *In-Between Days* reminds each one of us how beautiful life is, and what a gift. In her heartbreakingly honest exploration of these spaces in-between, Harrison provides a useful guide for those who cannot know the thoughts and fears of someone living with chronic illness; and for those experiencing a similar situation, the book shows that even in the most personal of journeys, you are not alone. At its heart, *In-Between Days* is a firm statement that joy and hope can exist in the same space as anxiety and fear; that each day we are given should be lived, as Harrison says, "With a sense of wonder and delight."--Michael Melgaard "National Post "



In 2013 **Lynda Bellingham** was diagnosed with cancer. Having kept the details of her illness private, now for the very first time Lynda talks with beautiful poignancy about her life since her diagnosis, her family and how together they came to terms with a future they hadn't planned.

Having been told that she only has a matter of months left to live and writing this in what will sadly be her final days, *There's Something I've Been Dying To Tell You* is a brave and brutally honest memoir and yet Lynda also manages to spread her infectious warmth and humour, bringing light to a very dark time. Woven into this very moving and brave story are extraordinary, colourful tales of her acting and family life that will enlighten and entertain as well as the journey that Lynda has taken to find the family of her birth father having already suffered heartache in her search for her birth mother. In the search for her father's family, Lynda finds a family with a history in entertainment showing that acting was always in the blood.

Lynda Bellingham is a tremendously gifted storyteller with a rich collection of tales of love, loss and laughter and this book brings her kind heart, courage and emotion to the page in vivid detail. Lynda's story is an affecting and at times heart-breaking one but it is so often laugh-out-loud too and ultimately the way Lynda tells her life story will serve as a great inspiration.

USEFUL INFORMATION

Association Siège Social

Mairie
Le Bourg
16350 BENEST

National Help-line
Telephone: 0800 240 200 (*local call cost*)

(your call is taken on an answerphone and is free - there is a short message in English - we will reply to you as soon as possible and normally within 24 hours)

Useful Contacts

President: Penelope Parkinson
president@cancersupportfrance.org

Treasurer: Stephen Hartley
treasurer@cancersupportfrance.org

E-mail: helpline@cancersupportfrance.org
Website: www.cancersupportfrance.org
Internet Forum: <http://csf-forum.org>

REGIONAL GROUPS

Alpes Maritimes (06, 83)	Angela Anderson	07 68 38 74 70	cancersupport06@gmail.com
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