



THE POWER OF WORDS

What to say & what NOT to say:
a guide for family, friends & supporters

PYNKS

A group for women living with
Metastatic Breast Cancer



breast cancer
research centre-wa



It's not easy news...

if your sister, mother, daughter, friend or work colleague has just been diagnosed with breast cancer or is having treatment for breast cancer.

You're not sure what to say, but you want her to know that you are there to help whenever she needs you and to wish her the best.

You might even want to offer helpful advice.

What most people don't realise is that while most breast cancer patients are offered support and sympathy – particularly at the time of diagnosis – they are also bombarded with comments and suggestions that are not helpful at all and can add to the despair.

Many people make comments without understanding the complexity of breast cancer.

Every woman's experience and treatment experience will be different.

Most of us know only what has come from reading women's magazines or watching current affairs shows – or from knowing someone who has had breast cancer. These avenues usually offer pretty limited information.

Most people have the very best intentions when they make comments or offer advice and would be appalled to find out that instead their words caused annoyance or added to distress.

Hopefully, you'll read this pamphlet before you say anything. It will tell you what NOT to say – or at least points to consider before 'putting your foot in it'.

It will also give you guidance about what to ASK. What you pass on to others is also important and there are some pointers about respecting privacy.

This guide has been put together in consultation with breast cancer patients. They have found that not everyone will react to the same comment in the same way, but they all believe their family, friends and supporters should consider the whole picture before offering comments or advice.



"How are you?"

A simple *How are you?* is fine, if said in the same way that you normally would when greeting a friend or relative...

But if questions delve further: *"How are you feeling? How is the chemo going? Is it working?"*, then you are starting to put pressure on a cancer patient to open up about their personal health problems.

It is a most personal matter that an individual has a right to NOT disclose. Some people subtly probe by voicing assumptions.

Comments that make assumptions, such as; *"You look great. You must be fine?"* may be stressful when things are not going well.

It assumes an answer will be given if the statement is not correct.

Any specific questions or comments should be left to the closest of relatives – mother, father, husband or very closest of friends.

If your friend wants to talk about these things she will mention them in her response to the milder question: *"How are you?"* and you can take it from there.

What to say:

- ✓ *How are you?*
- ✓ *How's things?*

(Don't probe further - Let the person lead the conversation and respect their privacy.)

What NOT to say:

- ✗ *What exactly is happening with your treatment?*
- ✗ *You look so well.*
- ✗ *You must be fine.*



Should I tell other friends, relatives and people in my community?

Never assume that your friend or relative who has just been diagnosed with breast cancer wants everyone to know.

Once you have disclosed the news to someone, then it can never be undone. You need to be very respectful of people's wishes in this area. Some people with breast cancer are very private and want to disclose to each person individually themselves.

If they lose hair during chemotherapy, they may wish to 'lay low' until it grows back or hire/buy a convincing wig. It is very important to first ask your friend/relative who they don't want to know, who they would like you to tell and what information they would like you to pass on!

Be very reliable on this, no matter the temptation to tell others or disclose more detail.

Certainly, don't post the news on Facebook or Twitter!

While some people are intensely private and cope best this way, other

people may select friends or relatives to spread the news to avoid the onus of telling people themselves, and to ensure that others do not make the many requests of them that would normally be the case.

Every situation is different.

It is also important that if you do talk about the person's breast cancer to anyone, that you are very careful that children aren't listening.

What to say:

- ✓ "Cathy, would you like me to let anyone know on your behalf?"
- ✓ "What would you like me to tell them?"

What NOT to say:

- ✗ "Cathy told me she has breast cancer. I thought you should know."



*Did they get it all?
Are you going to be alright?*

NEVER, ever ask this of anyone.

You don't need to know and your friend doesn't want to think about it, especially if "they didn't get it all..."

Fortunately, most women will have one round of surgery and treatment (whatever it is) and will never be visited by breast cancer again.

If they want you to know that the story is otherwise, then they will tell you in their own time.

For anyone diagnosed with Stage 4 breast cancer (incurable, when the cancer has spread to other parts of the body, such as bones or vital organs) it is an extremely traumatic time.

Usually they want nobody outside of closest friends and immediate family knowing if possible. Your friend/relative will desperately want normality and privacy.

They don't want everyone they know looking at them with pity and asking after their health.

Treatment will often keep Stage 4 (Advanced) disease under control so that your friend can lead a close to normal life.

What to say:

- ✓ "Do you want to talk about the treatment?"
- ✓ "Let me know if you want to talk about it."

What NOT to say:

- ✗ "Did they get it all?"
- ✗ "What's the prognosis?"
- ✗ "How long are you having treatment for?"



How to offer help

Friends and family invariably want to help, but there is only so much that anyone can do.

You don't have a silver bullet. Your help can really only offset a bit of the day to day inconveniences, but your small gestures may be a big psychological boost.

Small acts of kindness are most appreciated, whereas larger acts can be an imposition.

The most important thing is to not press help onto your friend or relative.

People with breast cancer should have the opportunity to agree or politely decline an offer.

It is sometimes difficult for the person with breast cancer to ask people to do things, such as accompany them to treatment, in case the friend or relative is not comfortable with it.

It is best for you to make it clear to your friend or relative what you would feel most comfortable doing.

Offer the support that you are happy to give, but don't insist. People with breast cancer still need their independence.

One example of unobtrusive help, given as an example by one patient: a friend offered to come over so they could

together pot up some of her needy pot plants.

It was mutually enjoyable and beneficial because the friend brought along her plants to repot as she helped.

What to say:

- ✓ *"May I help by taking you to hospital if you ever need it? I'm available on Tuesdays and Thursdays."*
- ✓ *"I'm happy to help by making a meal for you occasionally. I can make something that your whole family would like at the same time I make our own meal. Just let me know. I don't want to intrude."*
- ✓ *"Would you like me to drop by for tea and a chat sometime? Shall I ring first?"*

What NOT to say:

- ✗ *"I really think that I should take you to treatment. You shouldn't go alone."*
- ✗ *"I made this for you. Please eat it because I've noticed you've lost weight lately."*



Should I encourage them to get out more socially?

You may have noticed that your friend or relative has reduced her involvement in the social activities that you both enjoy.

You may want her to come along again because you want to see her have a pleasant contrast to treatment, but it is not as simple to participate as it might seem.

Breast cancer treatment often makes you tired and reduces your energy so that even the simple daily tasks of dressing and showering are an effort some days.

There are a lot of additional tasks that must be fitted in, such as doctors' appointments, visits to hospitals, blood tests and scans.

Each patient usually has a number of extra daily tasks to do at home to mitigate the many side effects of treatment, such as mouth washes to control ulcers, massage for lymphodema and special dietary preparations.

You need to consider that your friend or relative probably has quite significant

time and energy pressures and needs to be selective about what to attend.

Don't pressure her to get out more, but do keep inviting her to all the normal activities, even if she declines the first few requests.

Sometimes the request itself is uplifting, even if declined.

What to say:

- ✓ "We are going to a show next month. Would you like tickets? My sister can use them if you don't feel up to it on the day."
- ✓ "I am having a dinner next Saturday at 8pm. Just let me know by lunchtime on the day if you feel like coming."

What NOT to say:

- ✗ "You really should get out more!"
- ✗ "You **MUST** come on Friday. We really want to see you."

Be careful about the messages you send

Breast cancer patients receive very good medical care in Australia.

There are many types of breast cancer and there are many different treatment regimens available.

There are countless combinations of surgery, radiotherapy, hormonal pills and intravenous drugs, while treatment programs are individually tailored, generally with input from a whole medical team rather than one doctor.

You should trust their treating doctors that everything that the person with breast cancer is receiving is gold standard.

There are rare occasions, in complicated cases, when a second opinion may be warranted.

Your oncologist recognises that sometimes their patient may request one if they feel their treatment is not working or causing many side effects.

However, if a patient seems particularly unwell or in pain, and is the stoic type not wanting to complain, then it might be the occasion to check if they have asked their doctor if these problems are normal.

They may not have told them and remedies are at hand. Their oncologist should be happy to receive a phone call between appointments when a patient or primary carer is worried about something. There is usually a night time number for emergencies too.

You don't want those with breast cancer to feel that the treatment they are receiving is inadequate because of doubts you voice - it is most unlikely to be the case.

You may even be tempted to suggest they will do better if they work less or try harder to be healthy!

These suggestions can plunge a person with breast cancer into dark thoughts, so don't be the friend or family member who plants doubt about the person's treatment or lifestyle choices.

Be supportive instead and trust their medical team.

What to say:

- ✓ **(In most cases)** *"You seem to be receiving the very best of medical care."*
- ✓ *"You seem very unwell on this treatment, have you told your doctor that you are vomiting so much? There may be something he/she can do to make you feel better."*
- ✓ *"I've heard that some doctors don't mind a call after hours if you seem particularly unwell or in great pain."*
- ✓ *Has your doctor told you who to contact if you feel things aren't right?"*
- ✓ **(Rare)** *"If you don't feel your treatments are working, it is your right to seek a second opinion. Doctors are used to this, especially in complicated cases."*

What NOT to say:

- ✗ *"If I had breast cancer, I wouldn't be working."*
- ✗ *"I would have sought a second opinion."*
- ✗ *"If it was me, I would do EVERYTHING I could." (Another bad one, but sadly common.)*



Should I suggest some alternative treatments or supplements?

It is surprising how fervently people can believe in one alternative treatment that they have read about.

They may even become an agent for it. You might have read about the latest herb, vitamin or wonder food and really want the person with breast cancer to benefit.

You might believe that a complementary treatment, such as a type of yoga, meditation, massage or Reiki may really help.

These suggestions or pleas can easily become a daily occurrence for the person with breast cancer. They can feel bombarded with all this well-meaning information and feel stressed about not trying it all, particularly if they can't afford it.

The person with breast cancer starts to think, "What if it works?" and this adds psychological pressure. It is best if you leave it to the person with breast cancer to research these alternatives and choose those that appeal, in consultation with her medical team.

Some natural supplements can interfere with the drugs controlling the cancer or add to side effects, so the patient has to be careful. Echinacea and St John's Wort are among those.

What to say:

- ✓ "If you would like information on A, here is a pamphlet and website address. I shall say nothing more about it. I am just adding to your library of resources."
- ✓ "Would you like me to find out about the meditation and yoga sessions at the local hall? If you're interested, I'd love to go too, so maybe we can go together."

What NOT to say:

- ✗ "Cathy, I believe that X is REALLY good for breast cancer. You can do X, Y, Z."
- ✗ "I asked about meditation and yoga sessions at the local hall and they are on Wednesdays. I think you should go."



Other people's experiences

As we've said before, there are many different pathways through breast cancer and no one experience or disease is the same as another.

However, what all patients experience is uncertainty.

Most breast cancer patients will find their treatment has been completely successful and will never see it again, however individual patients do not know whether they are going to be one of this fortunate majority.

The future course and outcome of each treatment is often uncertain, and dealing with this uncertainty is one of the biggest challenges faced by a person with breast cancer. It is the cause of considerable stress.

Bear in mind that statistics on breast cancer, which are very good these days, do not remove the uncertainty for an individual.

Unrealistic expectations from friends and family – who place faith in

optimistic sounding statistics – can add to this stress.

It is best not to recount the stories of others' positive experiences, because they may have no bearing on what your friend or relative will experience.

Hearing lots of these stories can become overwhelming.

What to say:

- ✓ *"I have heard that everyone's breast cancer treatment is very different. I am thinking of you and wishing you all the best."*

What NOT to say:

- ✗ *"My aunt had breast cancer and she had this treatment. She's fine now just as I'm sure you'll be."*
- ✗ *"My colleague at work had breast cancer and it was all over in a few months; never saw it again. I am sure that will happen with you."*



One last thing...

Try to be as relaxed and as normal as you usually are when you talk to your friend/acquaintance/relative with breast cancer - and this advice is also for GPs and other professionals.

There's nothing worse than suddenly having people relating to you in a sombre manner once they realise you have cancer, especially when it is advanced, or trying to avoid you out of awkwardness.

One patient said that a locum GP immediately adopted a solemn, death bed manner once he became familiar with her serious condition.

Try and keep it light, guys!

Life is still good between the down times. Patients want to see a smile and hear a laugh more than anything!

Tip for the friend or relative with Breast Cancer: *How do I respond?*

Not everyone will read this guide and even good friends and relatives do say the wrong thing at times.

This can be distressing for the person with breast cancer and there is a temptation to respond emotively and worsen the situation.

Instead, why not try some politician's tricks, such as answering a completely different question, changing the subject, turning away and saying nothing or simply laughing and making fun of the response?

What to say:

Not everyone can play the political game so here is a reply that should cover most bases without offending anyone:

✓ *"Sorry, I just don't like talking about my health to people outside my family. I'm here to relax and have fun."*

About this guide

The Power of Words brochure is an initiative of BCRC-WA and articulates the principles that underlie **PYNKS**. This is a group organised by BCRC-WA for women with advanced breast cancer.

PYNKS is free and open to anyone living with metastatic breast cancer.

PYNKS derives its name from Positive, Young, Nurturing, Kids/family focused, Strength-giving ... words that sum up BCRC-WA's warm, friendly and welcoming social group for patients with metastatic breast cancer.

The Breast Cancer Research Centre – WA (BCRC- WA) proudly supports and co-ordinates Pynks and is the publisher of this brochure. BCRC-WA is the initiative of practising oncologist Professor Arlene Chan who is conducting a range of research and studies into various breast cancer treatments.

Join our PYNKS meetings to share and connect with others like-minded people who can provide understanding, friendship and support.

The Power of Words has been written and compiled by Karen and Louise, with **ideas** input from Professor Chan, Jane and Vicky.



For more information email: info@bcrc-wa.com.au information on BCRC-WA support groups or to donate please visit www.bcrc-wa.com.au

p 08 6500 5501

e info@bcrc-wa.com.au

Hollywood Private Hospital

bcrc-wa.com.au  



PYNKS

A group for women living with
Metastatic Breast Cancer

