

Preparing to Care: Woman to Woman

Are you ready for the unexpected?

Acknowledgements

'Preparing to Care: Woman to Woman' has been prepared by a group of women from the Inverness area who found themselves caring for their partners. They wanted to share their learning with other women who may find themselves in a similar position. The women came together as a group to take part in Engender's Equality Counting project, funded by the Equality and Human Rights Commission.

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Introduction

Men and women take a variety of caring roles and can face practical and emotional difficulties at times. The significant majority of carers in Scotland are women. Recent figures from Carers UK show that of Scotland's 668,200 carers, 414,284 (62%) were women and 253,916 (38%) were men. This leaflet is about the specific experience of women who find themselves suddenly caring for another adult.

It highlights some issues so that women can learn from others who have been in the same situation.

- What can I do to prepare in case it happens?
- What may be expected of me?
- What choices do I have?
- Where can I get information?

Action to consider now

Financial and legal matters

In many joint households men take primary responsibility for financial and legal matters. If they become incapacitated this can make it difficult for their partners handling day to day matters.

“You don’t need financial worries on top of everything else you are dealing with.”

- **Finances**

Discuss finances together so you know where everything is and you know what you have e.g. bank and building society accounts, investments, pensions, insurance policies.

Ensure that things like property title deeds, bank accounts and utility bills are in joint names.

“My husband was very much wanting me to pay attention to all these sort of things and I would say ‘a-huh’, but not really wanting to be bothered with it.....the number of times I was warned there will be a day that you have to handle these things and if you are not going to pay attention let it be on your own head.....”

- **Set up a power of attorney**

This means you give someone else the authority to make decisions on your behalf. This can relate to legal or financial matters e.g. accessing bank accounts and health and welfare matters e.g. decisions regarding medical treatment.

You can name up to four people as power of attorneys. Make it clear if they can make decisions on finances **or** health **or** both.

If a power of attorney is not in place when someone becomes critically ill or disabled and is not able to deal with these matters anymore it can be more complicated and expensive to arrange.

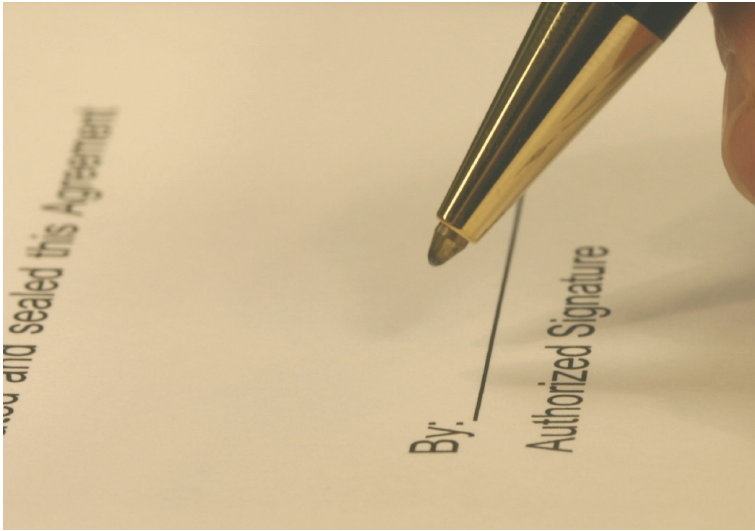
“If it had been in place it would have saved me £5000”.

A power of attorney needs to be in place to allow someone else to make decisions on your behalf e.g. to access bank accounts, deal with ongoing contracts such as a mobile phone. It can also allow someone to make decisions regarding your health and welfare.

If you have reciprocal power of attorney with your partner remember to change it if they become incapacitated. This means that there will be someone to take responsibility for your affairs if anything should happen to you.

Further information:

www.Stroke4Carers.org



- **Update your wills**

Make sure your wills are updated on a regular basis. If you become a carer you may want to change your will to reflect the new circumstances. The more complicated your own situation, the more important it is to make a will with the help of a lawyer. For example if you:

- have children from more than one relationship.
- if you own property or assets abroad.
- if you have owned your own business.

Further information

www.Stroke4Carers.org

- **Critical illness plans**

Many people take out insurance to cover them if they become critically ill.

Think carefully about the plan you take out, read all the small print and if necessary take advice. It can be difficult to get them to pay out even if you have paid the premiums.

“We were silly enough to think we were covered properly.....”

“There’s an awful lot of loopholes in the small print. We had to get the lawyer involved.”

Further information

<http://cancerhelp.cancerresearchuk.org/coping-with-cancer/coping-practically/money/medical-insurance#critical>

Independence

Lots of women are keen and confident drivers but if you are not one of them life may be more complicated.

“..... I could drive and I would say it was one of the saving graces... I can’t imagine how we would cope without it to be truthful.”

Knowing the wishes of your partner or relative

- **Funeral arrangements**

Discuss funeral arrangements. If you know what someone would like it is easier to arrange.

“Only conversation I ever managed was once. I know he didn’t want to be buried... he wants to be cremated and to take him up the top of Ben Nevis and set him free”

- **Resuscitation status**

If your partner or relative is ill in hospital you may be asked by the medical team whether they would wish to be resuscitated in an emergency. It is a much easier question to answer if you have discussed it and you know clearly what someone would want. Ask medical staff to give you an honest opinion about the likely outcome if resuscitation is attempted. In many cases resuscitation is not successful or may lead to further long term disability.

Further information:

www.Stroke4Carers.org



Becoming a carer

Women can find that they are expected to take the role of caring for a relative or partner. This can come from health and social care staff and other members of the family.

“It’s definitely seen as the woman’s role”.

“Because she is single and retired there is an expectation from her sister and brother that she does it. I don’t understand why... a sister who is married can share but a single woman is just expected to do it.”

Women may accept this with little discussion about alternatives or what support could be made available to ‘care for the carer’.

“At the time you are so pleased to have somebody dealing with you, you just accept what they say and go along with it..... that’s the problem”.

“A lot of it at the time you don’t have the time to think properly.....you assume they are the experts and you just go along because it is the easiest option”.

Useful things to consider:

Do you want to be the main carer?

Being a carer can be very tiring both physically and emotionally but it can also be very rewarding. If you do decide to take on the role of carer it is important to look after yourself. There are organisations that can help you and you are entitled to a carer’s assessment from social services to identify your support needs.

More information from:

www.Stroke4Carers.org

“We would all like to think we would like to be the carer but one life has been destroyed. What one needs to do is to speak to someone who has been the carer and not compare yourself with them because they can come across as ‘what a virtuous woman’ and am I a bad person because I’m not going to do it....”

“What I see now I did the right thing (with my husband going into a residential home) and if someone were to point the finger I would allow them to do that and turn round and say maybe I was thinking of myself but in fact I was thinking of my daughter, my son and my 5 grandchildren because there is no way that my husband would have been able to enjoy these people if he had been at home. His life was cut short. But by somebody giving up their life I don’t think that was going to make any difference to the person”.

- **Choosing to care at home or in care home**

When someone leaves hospital they may require significant levels of care. Does the individual go home with a package of care or move into a nursing home?

This can be a difficult time for everyone involved to make the right decision for both their relative and themselves.

Women may feel that it is expected of them to care for someone at home.

But both decisions are acceptable. You need to be honest with yourself as to what is possible and acceptable.

“If this is what is expected of you ... you are going to be a completely different person you are going to have a completely different relationship life is going to be with a lot of restrictions and to look for professional/help from someone who has had experience of it. “

The effectiveness of the transition from hospital and rehabilitation into the community is important for the well being and confidence of patients and their carers. It can be often mismanaged.

“Then on 14 December 2009 we unfortunately met the care company’s co-ordinator through hospital social work. Without any warning they blurted out to us in the day room “You’re going home on Monday” and my husband cried”.



- **Care at home**

“Going from the support of NHS to care at home is like going from day to night.”

If the decision is to have a care package at home ask about the different care providers available. You may have a choice and hospital staff should help you to make plans to cope with the move home. As there is a high demand for hospital beds people tend to spend shorter periods of time in hospital.

Ask lots of questions in the hospital when discussing care at home. Make sure that respite care is included. For anyone who has a long term condition or a condition which is likely to deteriorate respite care is crucial.

“I just listened and then said this is not a terribly honest message that you are giving me. You know you are offering me x, y, z and I think you need to be honest and realistic and you’re not being either. “

Consider self directed support which may give you more control over the type of care available.

Further information:

www.careinfoscotland.co.uk

Voluntary organisations such as Crossroads offer a vital additional service by taking over the caring responsibilities for a short period allowing the carer to take time to themselves.

Further information:

www.crossroads-scotland.co.uk

Carers centres provide information and support on all aspects of caring. They offer training such as first aid or moving and handling for carers as well as advice on benefits. They may have access to a befriending service if you cannot leave the person you are caring for and cannot get out to a carers meeting or may offer an advocacy service.

Further information:

www.carers.org

www.Stroke4Carers.org

- **Care homes**

Ask about Social Care and Social Work Improvement Scotland (SCSWIS - formerly the Care Commission) reports and ratings.

If you can rely on the quality of care in a home the transition *“would be easier to cope with. You would be happier in your own mind...(you wouldn’t feel less guilty).. guilt doesn’t come from there. It comes from walking away.”*

When visiting a home ask which exact room they will have.

Once in the care home make sure there is a care plan in place. Ask for it to be changed if necessary and cover all the details.

If you are not satisfied talk to them first and give them a chance to make changes before making a formal complaint.

Be careful about establishing a routine which is difficult to maintain e.g. visiting every day.

“Rest of family tell me not to go and see him every day... but he will be looking for me.”

Keep a record of everything that happens.

Keep a diary in the room to be completed by everyone visiting.



How will it impact on my life?

'Learning to care can be difficult. Suddenly you become one person living for two... Worst problem is living in fear 24 hours a day. My husband is prone to seizures and it is not easy to get used to that.... It may be a bit odd to say but thinking back it was like bringing home a new baby! The responsibility was overwhelming. We overcame difficulties with learning/determination/love. When I needed him he was there for me and this is my way of saying thank you for 20 fantastic years.'

"It's what is expected of a woman to do. But did he want me as a carer or did he want me as a wife?"

- **Loss**

There are websites and organisations which offer help after a bereavement. It is important to remember that there is no right way or wrong way to feel after bereavement. There is help out there when you are ready to seek it, even if it is months after the death.

“Allow yourself to go through the grieving process that you will feel for the losses and the changes it will bring to your life”

I’ve been given 2 ½ years to grieve before he died. I am where I am today because I was grieving all the time since he had his stroke. He was lost ... he was only a shell. I was going to visit everyday to visit this person who didn’t have the character, couldn’t communicate and I used to think please if there was only some way of getting into this world where he is.”

Further information:

www.Stroke4Carers.org

- **Change in relationship**

Many medical conditions such as stroke and brain injury can affect a change in personality. Tell someone if you are struggling to cope. Your GP, practice nurse, an advice line or your local carer centre should be able to offer you help and support.

“My husband when he goes to the toilet it’s me he shouts on....I think “oh no here we go again”. But what am I going to say to him... you know I don’t want to do it.... But he wants me to do it... he doesn’t trust the carers..... so I just have to get on with it..... if I wasn’t there he would let the carers do it.”

“Because he has the damage it would be easy for the carer to retaliate (if he got angry) and it would be labelled abuse. But it is not defined as abuse when the cared for is abusive.”

- **Family relationships**

As a female carer you may find you are managing the situation to protect your children as well.

Try to make time to involve other members of the family in discussions. This will include children who will have questions



too. Even if there are no easy answers sometimes not knowing is more frightening than taking part in the discussion.

“I had to be very careful I had to think not just for myself but I had to think about my daughter....how is she feeling and what's this like for her now her dad had had a stroke.

The only way I could do it was to turn the clock back to my own father. I'm so glad it didn't happen to me”.

- **Loss of friends**

Friends can be a vital source of support particularly for women.

“We did not know each other before but we just sat in the car park and cried.”

But if you are caring for a male partner or relative you may find their friends fall away. For example men often form their friendships at work and they can drop away when someone is no longer linked to the job.

“His best friend came and cried and he said “I can’t come and see him like this...”... they were in the services and you would expect them to stand by their own.... It makes me feel really angry.”

Friends can fall away if someone becomes disabled particularly if communication changes and it is more difficult to have a conversation.

“If they could see how much difference a short visit makes they would come..... when we went to the social group one or two would sit with us. But most people just come and say hello and then leave him. I can see from his eyes that he is hurt that they don’t include him anymore..... he won’t go to the club anymore because of it....so he – and me – we are more isolated ”

- **Aloneness**

As a carer you may feel isolated and alone. It might be difficult for other people to understand the changes in your life.

“It’s not lonely but aloneness.”

“Aloneness comes from feeling nobody knows, nobody understands what its like unless they have been in the same situation.”

“I’m married

I’m not divorced

I’m not separated

I’m alone”



Carers’ organisations often offer opportunities to meet with other people in similar situations. This can be a useful source of support.

How can others support me in this role?

Women carers often do not receive the support that they need as their role as a carer can be taken for granted? It is important to ask for support when you need it.

In the hospital

- **Information**

Ask as many questions as possible. Ask for all the help and information you can get and find support e.g. other carers on ward, support groups, carers’ centres, etc. Hospital staff will be able to give you information leaflets, etc.

“Learn all you can and do not be afraid to ask questions. You will be more confident about what is to come if you understand exactly what is happening....”

“Find out all avenues of help that are available. There is a great deal out there. I did not do this properly and it took a while to learn who could help us.”

You may feel that you have a lot of questions which are not being answered. Ask for an appointment with the doctor or lead nurse in charge when they can give you their full attention. In some hospitals you can communicate with the doctor in charge by e-mail or telephone.

- **Benefits**

It may be the first time you have had to try to access the benefit system. Be prepared to tell your story to a number of people before finding the right one to assist. This can be a minefield. Citizens Advice Bureau or your local carers centre can help.

“You don’t know what department to go to....you don’t know who to ask.....you get pushed from pillar to post....I was floundering....you are in such a state that you can’t think properly....it is the time factor as well when you leave the ward and you get home you are watching the clock because you’ve got to go back...”

More information:

www.Stroke4Carers.org

- **Advocacy**

It is sometimes difficult to take in information and make informed decisions if you are on your own. Consider taking an advocate or friend with you to meetings to discuss discharge, care planning and other key issues. Some care organisations can offer an advocacy service.

- **Information available**

There is a lot of information available on the internet about medical conditions and practical advice. Some of it can be overwhelming and frightening. Care organisations have detailed and accurate information on their websites and can answer a lot of questions.

Further information:

www.carersuk.org/scotkand

www.carers.org



- **Time for yourself**

Many women find they have little time on their own once they become a carer.

They may feel they have to visit their partner in a home every day.

Visiting someone in a hospital or care home visiting can be very tiring and you should not feel guilty if you miss a day. Try to let the person know you will not be in to visit so they do not worry. If possible, try to set up a visiting rota with family and friends.

"If the situation was reversed my brother wouldn't be coming to see me every day."

"I thought to myself Would my husband be in every day..... I don't think so."

Women can feel guilty about continuing to take part in activities they previously enjoyed and can feel they need to justify time taken for themselves. It is essential for your current and future well-being that you have a life outside of your role as a carer.

"look after your health and you as a person, read a book, have a haircut, go swimming, lunch with a friend."

