

Advocacy for Carers in Pembrokeshire

Final Project Report

December 2008



Acknowledgements

I would like to thank the members of the advisory group as well as the carers who gave their time and insights to the research. Thanks also go to the organisations that supported the research by distributing questionnaires and facilitating focus group discussions.

Content

Summary	4
Introduction	7
Definition and models of advocacy	8
Existing services	11
Results from the questionnaire	13
Distribution	13
Use of advocacy services	13
Need for an advocacy service	14
Support in caring role.....	16
The cared for and the carers	17
Themes from the interviews	19
The interviewees	19
Awareness of advocacy	20
Support that the interviewees are receiving.....	20
Situations when advocacy could have helped	22
What advocacy model would be best?	26
Focus group discussions	29
Advocacy services for carers outside of Pembrokeshire	30
Wales	30
Bridgend Carers Centre Advocacy for Carers.....	30
Hafal Mental Health Cardiff Carers Advocacy project	30
The UK	30
Lothian VOCAL Carers Centre Advocacy Service.....	30
Hampshire Carers Together Carers Advocacy Service	31
Carers Association in South Tyneside Carers Advocacy Service	31
Recommendations.....	32
Appendix	33

Summary

Introduction

It is estimated that there are approximately 15,000 carers in Pembrokeshire, many of whom need support/advocacy at times of major decision making or difficulties. In Pembrokeshire's Carers Strategy Action Plan, one of the action points is 'to develop advocacy support systems for carers'. There is no dedicated advocacy service for carers in Pembrokeshire, and there is concern that the advocacy services available to carers at the moment are not sufficient and not specific enough. The research aimed to establish what services are available, where the gaps are and what new or extended services should be provided.

Definition and models of advocacy

The following definition was used throughout the project:

An advocate is

- Someone who helps you to make **YOUR** voice heard
 - Someone who works under **YOUR** instructions
- Someone who is on **YOUR** side at a difficult meeting
- Someone who helps **YOU** to find the information you need
 - Someone who listens to what **YOU** want to achieve
 - Someone who helps you to work out **YOUR** choices¹
 - Someone who treats all information in confidence

Existing services

There is no advocacy service dedicated for carers in Pembrokeshire. Existing advocacy services as well as services for carers are outlined in the report. The organisations contacted unanimously supported the establishment of a dedicated advocacy service for carers and saw a need for such a service.

Results from the questionnaire

A brief questionnaire was designed with the aim to collect the views of carers on whether they saw a need for an advocacy service. The questionnaire was sent out with the Carers Gazette to all carers on PAVS' distribution list as well as through distribution lists of other organisations. Although the return rate was not as high as we had hoped, the questionnaires contained a lot of valuable information.

Most carers saw a need for an advocacy service and had been in situations when advocacy could have helped. The issues mentioned were mainly about:

¹ We thank Carers Together Hampshire for being able to use this summary of advocacy.

- finding out information about services and support that is available to carers, including benefits, and
- dealing with problems regarding services.

Themes from the interviews

Twelve interviews were conducted with carers from a variety of backgrounds to get in-depth views on the need for advocacy. All carers expressed strong support for an advocacy service.

Carers were in receipt of various support services and were generally happy with the services received. However, most interviewees had also experienced problems in the following areas:

- Finding out what support is available and what support they are entitled to (especially when starting to care)
- The support that they receive (problems with individual paid carers, problems with the NHS, the statementing process, respite care, benefits, housing...)

Interviewees said that they do not like to complain. Reasons given were:

- anxieties that a complaint would threaten the services they are receiving
- lack of knowledge who to complain to and how to go about it
- feeling that others are much worse off than they are and that their problem is not serious enough

Most interviewees said that advocacy would have helped them when they were going through problems. An advocacy service was seen as an independent outside party who would be able to fight the carers' corner. An advocacy service was also seen as a one-stop-shop for carers to find out what support is available and what support carers are entitled to. Many interviewees said that an advocacy service should start working with carers at the very beginning of their caring role, for example the birth of a disabled child or the illness or hospital discharge of a relative. Early contact with an advocacy service was seen as a chance to prevent any more serious problems.

Most interviewees felt strongly that a professional advocacy service was needed. Professional advocates were seen to have the necessary expertise and status to be effective in sorting out problems. Many interviewees made it clear that they would only use an advocacy service for a really serious problem, and that they would try their best before asking for help.

Focus group discussions

Three focus group discussions were held as part of meetings of carers support groups. The carers supported the setting up of an advocacy service for carers. The discussions covered many issues that had been raised in the interviews.

The following issues were raised in addition:

- Concerns were raised that often surveys and research is carried out with no real outcome that benefits carers.

- An advocacy service should make sure to access the different groups of carers and to offer the expertise required (carers of different ages and different ages of cared-for people, carers of different groups: people with learning, physical and sensory disabilities, mental health problems)
- An issue of concern that an advocacy service for carers should address is the benefit system, help with filling forms, understanding the system and campaigning for increased amounts of money going to carers

Recommendations

- An advocacy service which is accessible for all carers should be established in Pembrokeshire.
- The advocacy service should be a 'one stop shop' where carers can get a complete range of information on support and benefits that are available. Any new advocacy scheme should link in with existing carers support services.
- Advocacy should act as early as possible, ideally from the very start of the caring role, to support carers when they need it and to prevent conflicts.
- The advocacy service should be an independent and professional service ensuring expertise, status, appropriate training and supervision of the advocates, as well as confidentiality. To ensure this, any newly established advocacy scheme should follow the Action for Advocacy Charter.
- An advocacy service should make sure to access the different groups of carers and to offer the expertise required (carers of different ages, carers of different groups: children, adults and older people with learning, physical and sensory disabilities, mental health problems).
- An advocacy service should be accessible for carers from all locations in Pembrokeshire.
- An advocacy service should include young carers and/or work closely together with existing services for young carers.
- An advocacy service should work in a flexible way to meet the needs of carers.

Introduction

It is estimated that there are approximately 15,000 carers in Pembrokeshire, many of whom need support/advocacy at times of major decision making or difficulties. In Pembrokeshire's Carers Strategy Action Plan, one of the action points is 'to develop advocacy support systems for carers'. There is no dedicated advocacy service for carers in Pembrokeshire, and there is concern that the advocacy services available to carers at the moment are not sufficient and not specific enough. The research aimed to establish what services are available at the moment, where the gaps are and what new or extended services should be provided.

Funding was secured from the Carers Contingency Fund. An advisory group was established with carers representatives, the PAVS Carers Development Worker, representatives of organisations working with carers as well as statutory sector partners. As part of the research meetings were arranged with local organisations that were either advocacy providers or working with carers to find out what advocacy services are currently available for carers. To find out what carers feel they need a questionnaire was sent out to all carers on the PAVS mailing list (approx 850 carers). To follow this up 12 in depth individual interviews were conducted with a sample of carers. In addition three focus group discussions were held to discuss findings from the research and get feedback on suggested models for advocacy service.

The findings from the research are reported here. First, a definition of advocacy is given and models of advocacy are described. Second, advocacy services existing in Pembrokeshire and other services of relevance to carers are mapped. Third, the results from the questionnaire and the findings from the interviews are detailed. Forth, examples of carers' advocacy schemes from other counties are given. In conclusion recommendations are given for the development of an advocacy service for carers in Pembrokeshire.

Definition and models of advocacy

Since advocacy is not a term that is widely understood and that is used expressing different meanings, it was felt that a clear definition was needed to explain advocacy to the research participants. The following definition of advocacy was used on the questionnaire and on information sheets for the interviews and focus groups (see appendix). The definition was adapted from one used by a carers project in Hampshire for a similar purpose.

An advocate is

- Someone who helps you to make **YOUR** voice heard
 - Someone who works under **YOUR** instructions
 - Someone who is on **YOUR** side at a difficult meeting
- Someone who helps **YOU** to find the information you need
 - Someone who listens to what **YOU** want to achieve
 - Someone who helps you to work out **YOUR** choices²
 - Someone who treats all information in confidence

Central to the role of an advocate is that he or she is independent of any service provision and that he or she works strictly under the client's instructions. The role of an advocate can encompass diverse activities, such as making phone calls on the client's behalf, writing letters, filling in forms, finding out information and attending meetings.

Most advocacy providers work to the standards set by Action for Advocacy, a UK-wide organisation supporting advocacy services. Action for Advocacy have developed the standards in collaboration with advocacy providers. They are set out in the Advocacy Charter³:

'Advocacy is taking action to support people to say what they want, secure their rights, represent their interests and obtain services they need. Advocates and advocacy schemes work in partnership with the people they support and take their side. Advocacy promotes social inclusion, equality and social justice.

Clarity of Purpose The advocacy scheme will have clearly stated aims and objectives and be able to demonstrate how it meets the principles contained in this Charter. Advocacy schemes will ensure that people they advocate for, service providers and funding agencies have information on the scope and limitations of the schemes' role.

² We thank Carers Together Hampshire for being able to use this summary of advocacy.

³ This summary is taken from Advocacy on your marks: Standard support project, Action for Advocacy, p. 8, for more information see www.actionforadvocacy.org.uk

Independence The advocacy scheme will be structurally independent from statutory organisations and preferably from all service provider agencies. The advocacy scheme will be as free from conflict of interest as possible both in design and operation, and actively seek to reduce conflicting interests.

Putting People First The advocacy scheme will ensure that the wishes and interests of the people they advocate for direct advocates' work. Advocates should be non-judgmental and respectful of peoples' needs, views and experiences. Advocates will ensure that information concerning the people they advocate for is shared with these individuals.

Empowerment The advocacy scheme will support self-advocacy and empowerment through its work. People who use the scheme should have a say in the level of involvement and style of advocacy support they want. Schemes will ensure that people who want to, can influence and be involved in the running and management of the scheme.

Equal Opportunities The advocacy scheme will have a written equal opportunities policy that recognises the need to be pro-active in tackling all forms of inequality, discrimination and social exclusion. The scheme will have in place systems for the fair and equitable allocation of advocates' time.

Accountability The advocacy scheme will have in place systems for the effective monitoring and evaluation of its work. All those who use the scheme will have a named advocate and a means of contacting them.

Accessibility Advocacy will be provided free of charge to eligible people. The advocacy scheme will aim to ensure that its premises, policies, procedures and publicity materials promote access for the whole community.

Supporting Advocates The advocacy scheme will ensure advocates are prepared, trained and supported in their role and provided with opportunities to develop their skills and experience.

Confidentiality The advocacy scheme will have a written policy on confidentiality, stating that information known about a person using the scheme is confidential to the scheme and any circumstances under which confidentiality might be breached.

Complaints The advocacy scheme will have a written policy describing how to make complaints or give feedback about the scheme or about individual advocates. Where necessary, the scheme will enable people who use its services to access external independent support to make or pursue a complaint.'

Action for Advocacy discusses the following main models of advocacy⁴:

Citizen advocacy Citizen advocacy was developed in America and became formalised in the UK in the early 1980s. It is based on

⁴ Advocacy on your marks: Standard support project, Action for Advocacy, p. 10

Professional, one-to-one, short term, issue based or crisis advocacy	<p>one to one partnerships. An unpaid advocate works with someone on a long term basis.</p> <p>When an advocate speaks up for someone about a particular issue, or speaks up for them to help them through a crisis.</p>
Self advocacy	<p>When someone speaks and acts for their self to present their case. Many self advocates have come together to form a collective voice on issues that impact on their lives. This is also sometimes called group advocacy.</p>
Peer advocacy	<p>When the advocate has something in common with the person they are advocating for. For example, the advocate might be a user of a former user of the advocacy service.</p>
Non-instructed advocacy	<p>Taking affirmative action with or on behalf of someone who is unable to give a clear indication of their views or wishes in a specific situation.</p> <p>For example, this could be someone with dementia, profound learning disabilities or brain damage.</p> <p>The non-instructed advocate seeks to:</p> <ul style="list-style-type: none"> uphold the person's rights; ensure fair and equal treatment and access to services; and make certain that decisions are taken with due consideration for their unique preferences and perspectives.
Independent Mental Capacity Act Advocacy (IMCA)	<p>Advocacy for people who do not have the capacity to make their own decisions or have close friends or relatives who can speak up for them. IMCAs support these people through issues around medical treatment or residential care.</p>
Legal advocacy	<p>This is provided by lawyers and aims to assist people to exercise or defend their legal rights. For more information about legal advocacy, see www.legalservices.gov.uk</p>

Existing services

The following table details advocacy services that are currently available in Pembrokeshire. The table is not comprehensive, there will be other organisations and individuals that might provide advocacy, for example national condition-specific organisations or organisations that support carers in other ways as well as organisations that have a more general advice role such as the Citizen's Advice Bureaus.

Organisation	Service	Target group
Mental Health Advocacy Pembrokeshire (MAP)	Advocacy	People with mental health problems of all ages; Independent Mental Capacity Advocate (IMCA) service is to provide independent safeguards for people aged 16 years or older who lack capacity to make certain important decisions
Pembrokeshire Advocacy	Advocacy	People with learning disabilities aged 16+, have to be registered with the Learning Disabilities Team (Social Services)
Connect DRA	Advocacy	Disabled people, mostly aged 16+
Community Health Council	Help, advice and advocacy	Individuals who have problems with, or complaints about, NHS services
Carers Outreach	Provide information, advice and support	Carers of all ages and to former carers
Action for Children (was NCH)	Keyworker scheme	Families with children with severe disabilities receiving services from at least two agencies
Crossroads	Provide short respite breaks for unpaid carers, free of charge	Carers of adults with disabilities and chronic illness
Age Concern	Support, information and advice	People aged 50+
Hafal	Support	People with mental health problems and their carers

All the above organisations were informed about the research and asked whether they saw a need for an advocacy service for carers. They unanimously supported the establishment of a dedicated advocacy service for carers and saw a need for such a service. The advocacy providers felt that they reached their limits in cases when there was a conflict of interest between the cared for and the carer. In those cases their priority lies naturally with their clients, the cared for. None of the organisations work specifically for carers, although many will try and help even if this is strictly speaking not within their remit. The organisations working to support carers, like Crossroads and Carers Outreach, reported that they were often contacted and asked to provide advocacy, but that they did not have sufficient resources to do so. All of the organisations felt that if there was an advocacy service specifically working for carers they would have cases to refer to it.

Results from the questionnaire

A brief questionnaire was designed with the aim to collect the views of carers on whether they saw a need for an advocacy service. The term advocacy was explained in the beginning, carers were asked whether they had ever used an advocate, how useful that had been, whether they had ever felt they needed an advocate, and if yes in what situation. They were also asked about other support services they received in their caring role and finally to give some details about themselves and their cared for (see Appendix for Questionnaire).

Distribution

The questionnaire was sent out with a Carers Gazette to all carers on PAVS' distribution list as well as through distribution lists of Crossroads and Hafal. Some questionnaires were taken to the Carers Roadshow. The numbers as well as return rate is given in the table below. Although the return rate was not as high as we had hoped, the questionnaires that were returned contained a lot of valuable information and were filled in with care.

Number	Via	Returned	Comments
Appr. 700	PAVS carers list, sent with carers gazettes	61 (response rate appr. 7% - assuming distribution of 850 questionnaires)	Not all of those go to carers, they also go to professionals and statutory sector organisations
Appr. 100	Crossroads carers list		
100	Carers Roadshow		
50	Hafal		

Use of advocacy services

Out of the 61 carers who had returned the questionnaire, 11 had made use of an advocate. One of the carers gave details of a carers respite service, this answer has not been included below. The table below gives details of the organisations that delivered the advocacy service, the issue that was addressed and how helpful the carer felt the advocate had been.

Organisation	Issue	How helpful (1 - very helpful to 5 - not much help)
Alzheimer's Society	Making a will	3
Help the Aged	Overcharging of a nursing home	1

Organisation	Issue	How helpful (1 - very helpful to 5 - not much help)
MAP	Living will	1
PAVS, Social services	Respite for my son and getting positive behaviour team involved	1
NCH and Ty Hafan	Medical problems and appointments and reviews	1
CAB	Benefit for my husband and myself	1
Community Health Council	Inadequate treatment & support relating to provision of mental health services by NHS - still working on resolution	1
NCH, Sense	Education, child support	3
Pembrokeshire Carers Outreach	General help and advice when starting caring	2
MAP	My husband had psychotherapy at Bro Cerwyn, when person retired they did not take anyone on to replace in that treatment.	1

It is noticeable that most of the issues mentioned by carers regard the people they care for, and not themselves as carers.

Need for an advocacy service

34 carers who returned the questionnaire said they had been in a situation when they had needed the help of an advocate. 15 carers said that they had not needed an advocate in the past, one added 'maybe' and another one added 'not yet'.

The table below described the situations when carers felt they would have needed the help of an advocate:

Situation
My husband thinks he should go into residential care, but I don't agree and I think his doctor agrees with me.
In dealing with community nurses - luckily I have an excellent GP and a brilliant District Nurse who helped me. Input from community nurse - nil.
Housing issues with local authority. Benefit applications.
Getting to the people who are supposedly there to help you.
Information that we needed, when husband was still in hospital, I could find NO help, the hospital social services were useless. We had problems with the

Situation
attitude and so called care from one of the physiotherapists and complained - hospital made a united front and dismissed our complaint as untrue and foolish. No voice.
Research
Applying for benefits, dealing with health issues
Find information
In dealing with faceless organisations who have only rules and no common sense when dealing with individual cases, as all cases are different.
We as a family single mum three children had got to a crisis situation.
When my mother was first diagnosed with her illness, I think that it would have been beneficial to have someone present at meetings with the CPN and social worker who was less emotionally involved, and so more able to get the right information.
To discuss feelings and frustrations of health care for (my son) and my own frustrations of not being in a position to return to work... When you just stop your career it is frustrating not feeling able to join the normal day to day life.
To be given help in finding where to go for advice and information: medical concerns, benefit available, concessions, bus passes, someone to speak on our behalf.
Dealing with DSS problems. Help with finding solutions to the various health and mental health problems I deal with every day, and don't know where to turn for help.
Dealing with financial institutions/debt advice.
My husband suffers from depression - I have been his carer for twelve years. Last year he was stricken with G.B.S. as a result is now paralysed. He has been in hospital for 10 months and is due to be discharged shortly. I also have a heart complaint and awaiting an operation & need care myself. I felt the need for an advocate to help me re care package meetings. I was advised to get in touch with Bro Cerwyn but they were unable to help me at all. As a result I feel totally lost & confused & very much alone.
To represent a carer when an allowance or grant is refused or rejected to act in an appeal on behalf of a carer. To represent following a possible medical decision which caused/causes health problems.
I've received advice from carers UK helpline re finances. When you need assistance to obtain further help, either material or financial, for the person you care for. Help work out direct payment for cared person.
My partner tried to get back to job after long period of time. But because of his history of mental illness he was many times turned down. He also was bullied at his part-time job he had done a short period of time, due to his past and present illness.

Situation
We have to go to Carmarthen hospital every Tuesday for my husband to have psychotherapy - it will be 12 months in July.
Day care solutions.
All aspects of support for me, my children and husband.
The appropriate services that give the right provision for my son who has Asperger Syndrome Disorder.
Someone who helps you work out your choice.
Talking to different services and trying to get heard.
I feel every carer should have advocacy as well as the person they care for. Carers often become carers without realising it.
To know what I can claim for when your partner is disabled.
When I moved into Wales to look after my caree I needed to know my position as I was moving into his home and giving up my council house in London and was worried about my security.
When partner became ill (bi-polar) and was sectioned St Caradog's Hospital H'west felt completely helpless - did not know what to do - or who to turn to for help!
In dealing with assessments. I would not use an advocate who would not be fully understanding of our circumstance. Advocacy is all about trust and needs professional, informed understanding.

The issues mentioned above fall mainly into two categories:

- finding out information about services and support that is available to carers, including benefits, and
- dealing with problems regarding services.

It is noticeable that all the issues mentioned are serious and important. Information gained in the interviews supports this very much (see below).

Support in caring role

Most carers who returned the questionnaire mentioned at least one source of support. The table below details the support that was mentioned.

Support	No
Crossroads	19
Social Services	8
Hafal	8
Paid careworkers (through Social Services)	6
Day centre (through Social Services)	5
Respite care (through Social Services)	4

Support	No
Other health services	3
Community Psychiatric Nurse (CPN)	2
Age Concern	2
Direct Payment and ILF	2
Carers support groups	2

The following organisations were mentioned by one carer respectively: Mind, Alzheimer's Society, Holiday breaks for carers through PAVS, CAB, Ty Hafan hospice, Cars for carers, NCH, Barnardos, Sense, National Deaf Children's Society, Pembrokeshire Carers Outreach, Circle Network, MS Society - Hope MS Therapy Unit.

The cared for and the carers

The following tables give information about the persons cared for as well as about the carers who filled in the questionnaire

Person you care for		2nd person you care for	3rd person you care for
Adult with a learning disability	7	1	
Adult with a mental health problem	15	3	1
Adult with a physical disability	13	1	
Children	4		
Older person	16	1	1

Age of the person you care for	
under 18	4
18 to 24	5
25 to 49	7
50 to 64	11
65 to 84	19
85 plus	9

Age of carer	
25 to 49	11
50 to 64	26
65 to 84	21

Out of the 61 carers who returned the questionnaires, 45 said they were happy to be contacted about the research, while 8 did not want to be contacted. The interviewees were selected from the 45 carers who agreed to be contacted.

Themes from the interviews

To get more in-depth information from carers about their views on advocacy twelve interviews were conducted. A brief interview guide was developed with questions about the caring experience, support that the carer received, situations when the carer would have needed the help of an advocate, and views on what model of advocacy would be most effective (see appendix for interview guide). Carers with a variety of backgrounds were selected, male and female, of different ages and caring for people with a variety of problems. Some of them lived in rural isolated locations and some lived in the urban centres of Pembrokeshire. Three carers were caring for more than one person. Details are given below. All carers that were contacted and asked whether they would be willing to be interviewed agreed and were committed to give their views on advocacy. All carers expressed strong support for an advocacy service, even the few carers who thought that they themselves might not need such a service. This is discussed in detail below. The interviews lasted between half an hour and one and a half hour. With permission from the carers the interviews were recorded. Confidentiality was assured and the carers were informed that the recordings would be deleted after the project was finished.

The interviewees

No	Interviewee	Cared for
1	F, 30s, town, South Pembrokeshire	5 children under 18, all with special needs, and husband, has been unwell for the last 18 months
2	M, 70s, town, South Pembrokeshire	Wife, 80s, physical disabilities
3	F & M, 40s, town, Mid Pembrokeshire	Son, 6, chromosome disorder, deaf-blind and developmental delay
4	M, 50s, rural, North Pembrokeshire	Mother, 80s, Parkinson's
5	M, 50s, town, South Pembrokeshire	Son, 30s, with learning and physical disabilities, daughter, 20s, with learning disabilities and wife, 50s, a form of early onset dementia
6	F, 50s, rural, North Pembrokeshire	Mother, 90s, frailty and dementia
7	F, 50s, rural, South Pembrokeshire	Partner, 50s, mental health problems
8	F, 40s, rural, North Pembrokeshire	Mother, 70s, stroke
9	F, 70s, rural, South	Daughter, 30s, learning disabilities and

	Pembrokeshire	epilepsy
10	F, 60s, rural, South Pembrokeshire	'Adopted' son, 30s, mental health problems
11	F, 60s, town, Mid Pembrokeshire	Husband, 70s, stroke
12	F, 40s, rural, South Pembrokeshire	Husband, 40s, chronic depression, and son, 20s, diabetes and depression

Cared for	No of interviewees
Children (< 18)	2
Adult with a physical disability	4
Adult with a mental health problem	4
Adult with a learning disability	2
Older person (>65)	5
More than one cared for	3

Awareness of advocacy

Most carers interviewed had a good or excellent idea of what advocacy was. Some of them had made use of advocacy services for the person they cared for (see below). The interview served to increase this awareness. In addition, all interviewees were made aware of the services that PAVS offers (Carers Gazette and Carers Holiday Breaks) and asked whether they would like to receive information. Some carers had additional questions about other services. These were followed up after the interview with the help of PAVS' carers' development worker.

Support that the interviewees are receiving

Most interviewees had built up a good network of care and support. This includes support from the following sources:

- Social services
- Health services
- Voluntary sector services: Crossroads, Mind, Hafal, Pippa, Arthritis Care, NCH, CAB, PAVS
- Advocacy services: MAP, Pembrokeshire Advocacy, NCH, Hafal, Age Concern, CHC, Sense, SNAP Cymru, Carers Outreach
- Family, neighbours, friends
- Other carers

Most interviewees were generally positive about the support they receive.

'We are lucky because we have NCH and if we didn't have NCH I don't know where we'd be. But with NCH, they are brilliant. They supported us through a lot of problems like when (our son) went to school and was statemented.'

‘Social services have been excellent. They have pretty much done anything I have asked.’

‘We have had a lot of support from Hafal which has been absolutely wonderful, we can’t speak too highly of them.’

However, most interviewees had also experienced problems in the following areas:

- Finding out what support is available and what support they are entitled to (especially when starting to care)
- The support that they receive (problems with individual paid carers, problems with the NHS, the statementing process, respite care, benefits, housing...)

‘They don’t teach you how to care.’

‘You know what you are supposed to do, but there is no book to tell you whether you are doing it right or wrong. A lot of people tell you it’s common sense, and yes, it is common sense, but you think to yourself, where do you go to get help. The council give you a directory with all the organisations that you can contact, which is sound, which is a good basic. But then, as an individual who is perhaps not very clever, you think to yourself, if I phone them up and ask them about this, will it sound daft.’

‘But on the other hand you still think I’m x number of years old I should know this myself. But you can’t. It’s like knowing what you are entitled to. You talk to different people and different people get different things. The only way to find out is to go and ask the criteria. And perhaps when you’ve still got the same criteria as somebody else, and they get it and you don’t. And that doesn’t make sense to me.’

‘In terms of the caring, I suppose I don’t know what’s available to me. I’ve sort of been finding out things in dribs and drabs.’

Carers described many examples when they had problems with services they received, benefits or housing. To retain confidentiality it is not possible to provide detailed quotes here.

Interviewees said that they do not like to complain. Reasons given were:

- anxieties that a complaint would threaten the services they are receiving
- lack of knowledge who to complain to and how to go about it
- feeling that others are much worse off than they are and that their problem is not serious enough

'You see, I won't fight. Although it's for mum, I don't want to fight because I don't want to lose what I've got. I don't want to lose the bit of help that I get, whichever shape or form it comes in. If I want it altered and you ask people things there is always the answer, 'oh it's going to cost us so much money, we can't afford it, we can't do it because of this or of that'. They don't ask why you want it changing which might help sway your case. I think it's a good idea (the advocacy service).'

'It's definitely a good idea because you feel so, well I don't want to complain so much because I might lose what I've already got and you just don't want to do that. You can't complain when you are in the lap of somebody else. If I was basically like a lot of people if you could stand up and shout, and get what you want, perhaps it works for most people, but I always find when I stand up and shout and bang the table, it always backfires on me. So if you had a third party to say, well, I've been reviewing so and so, it doesn't actually bring that person into it, and I don't think it's right, what are you going to do about it. It takes all the pressure off the individual who has got the problem.'

Situations when advocacy could have helped

All interviewees expressed strong support for a dedicated advocacy service for carers. They all saw a definitive need for such a service. Even the interviewees who stated on the questionnaire that they did not need such a service themselves were supportive in the interview.

'We think advocacy is crucial, it really ought to be provided in Pembrokeshire, certainly from our experience we would back that idea.'

'I would definitely say there is a need, without a doubt. Because really we drop off the work list, the minute you become a carer you drop off the work list because you can't do, I couldn't go to work 9 to 5, so you become a little bit housebound, with me it's different because I work from home. But without that you lose confidence. You lose the confidence in yourself that you are capable of doing the job before you became a carer. I think you are viewed differently, when somebody says, 'what do you do.' 'I'm a carer' 'Oh.' Whereas if you say, oh I run ICI or I do this, you'd be looked at differently. Well you shouldn't be looked at differently, because you have given up your job to become a carer.'

‘Advocacy is very important, it means that the authorities can’t get away with things. Just because you don’t know what line to go down to sort things out. Whereas an advocate does, because they’ve got nothing else to do but know where you stand. I think it’s a very good idea.’

Most interviewees said that advocacy would have helped them when they were going through problems. An advocacy service was seen as an independent outside party who would be able to fight the carers’ corner.

‘And we as carers, lets face it, we have mental health issues, I know I certainly have. People see my character and they think yeah, but they don’t hear me at night crying or having panic attacks. And I think you can’t deal with your affairs then.’

‘I think that when I talk to the council, I had to go to Fishguard to a meeting with these three people, first of all you always feel disadvantaged because I don’t know the ins and outs of the law and what they are supposed to provide, they have a Care Charter or something, I don’t know what you can actually say, you can say ‘I’ve got the legal right to refuse a carer, you’ve got the legal duty to provide one for me, just get off your backside and do it.’ I don’t know, whereas somebody who does nothing but that, before you go into a meeting.’

‘I’ve learned over the years that if you don’t speak out you don’t gain anything. So I’m quite a tough cookie now. You have to shout a bit, and I wasn’t brought up to shout a bit, I was brought up very correctly. But you have to start not throwing your weight about, but fighting your corner. An advocacy service could have helped me in the past. Not so much now because I tend to go in with both feet, and if you’ve had 37 years experience you get quite tough. Not hard, but tough. But it would have helped me when (my daughter) was young, because I didn’t know what was available. I was brought up in a family where we looked after our own, nobody went into a care home, even when they were old and frail. When you had a disabled child, you looked after them. So I was brought up in this atmosphere that (my daughter) was my child that I looked after her. And gradually I realised that no, I shouldn’t have to do all this myself.’

‘I used to work in social services in a senior position before I was retired on health grounds, but that didn’t mean I lost my skills. I think I was better equipped than most to deal with the situation but even for me being involved in this kind of situation was very difficult and I could have done with all the support that was available. But there was no support available.’

'What I think I should have had as the carer and somebody who tried to fight his corner for him (her partner), as soon as he was there (admitted to mental health ward) I should have been told, these are your rights. These are the people you can contact if you need support. I appreciate people can't be everywhere at once, but it would have been nice to have been able to have had contact with somebody over the phone, at the least.'

'In terms of advocacy and carers, I know I do get overemotional, I know I do.'

'We never got the chance to be heard.'

'But it would be nice if you are entitled to something for somebody to pick up the baton for you, perhaps they would know what you are entitled to. 'Yes, I reckon you are, leave it with me, and I don my armour and go for it.'

'The biggest benefit we could get out of an advocacy service would really be for the knowledge that they know, rather than me having to research and find out something. If they already know the information they can then pass it on to me and I can then use it for whatever reason. Half the time as carers you either find out through word of mouth, or you try a government site and there is so much information on that site you could spend the whole day just looking through that and never find what you are actually looking for. What I find a lot is that they change the system every so many years.'

'I think an advocacy service would be good especially for new carers who are coming on. I've got twenty odd years experience of being a carer so I know quite a lot. And I spend a lot of time explaining it to other carers, but I don't know everything. And obviously I know what I'm dealing with personally, but their situation might be slightly different.'

Some carers had made use of advocacy services for the person they cared for. Most of them found that this had been very helpful.

'That was very good, they came round and they did all the forms and everything. They actually checked various websites, because there is a plethora of information out there but it's shifting through the rubbish and getting to the bits that's actually any good. And obviously when you are a carer your time is limited to say the least.'

‘We’ve had advocacy from the Community Health Council when we made the complaint and they have been wonderful.’

‘Every time I tried to talk about it I cried, and that’s one reason... And every time I tried to ring him I cried and shook. So I said to my son’s CPN we’ve got to get this dealt with, could you get him an advocate. So I’m not involved, not being the mum you see. And the woman who came was amazing.’

An advocacy service was also seen as a one-stop-shop for carers to find out what support is available and what support they are entitled to.

‘I think what you could do with is a one stop shop. If you become a carer you have a one stop shop and one person, who’d have to be rather clever and couldn’t be me, would have to know a bit about everything. To say the person you are caring for, whether they are 5, 15 or 85, go into different slots. So well for you, we should be able to do so and so, what have you already got, you need so and so, we can get you that. And then hand to one of the other four behind them, so that they can actually concentrate on it. So the person in front is fielding the enquiries and put them in slots.’

‘In terms of advocacy, I don’t know what there is for me to ask for, let alone I need someone to hold my hand, sometimes I need someone to hold my hand sometimes I don’t. The information would be what I would need most, because what is there to ask for. What I would find helpful, and I did try it through the social services, and I thought she knows less than I do, is benefits advice. Because if you get this benefit you can’t get this one, which is the better one for you to apply. What benefits are available, are they worth applying for, do you lose anything else.’

‘And nobody comes forward and tells you, you are entitled to this or you are entitled to that, you have to apply for them.’

‘Advocacy in the sense of someone holding my hand, speaking on my behalf and explain what I want, for myself I can see a more limited requirement. I am reasonably intelligent and articulate, and I can write a good letter. For my personal needs I want a one stop shop where I can be told what is out there for me, what I can apply for, what’s worth thinking about, what services are there, and a benefits adviser.’

Many interviewees said that an advocacy service should start working with carers at the very beginning of their caring role, for example the birth of a disabled child, the diagnosis or hospital discharge of a relative. Early contact

with an advocacy service was seen as a chance to prevent any more serious problems.

‘But I think the advocacy is a very good idea. But it must be picked up at the beginning, not half way through.’

‘It’s a shame that there isn’t an organisation that you could go to that would say, we need this. Or when they know a situation is coming up, like a child going to school for the first time and needs statementing, that they get in touch with the family and find out whether they need support. Because that’s one of our biggest things, that you’ve got to go out and search for the support.’

‘We’ve had advocacy from the Community Health Council when we made the complaint and they have been wonderful. But it might not have got to the situation where we made a formal complaint if we had had the help in the first place. So it’s actually costing the authorities a great deal of money when people are bringing complaints. What advocacy does is to prevent that situation from happening. People are talking about how much money it costs but you think what it costs the authorities for us to make a formal complaint through the Community Health Council, to get top managers to meetings and to deal with all the stuff that we put in front of them, because we weren’t prepared to have had our lives put at risk, which we feel happened. And because I think a lot of people who get into a situation like this have not had authority within the public sector like both of us have had prior to our retirement, and if it’s scary for us, what’s it like for other people. So we thought no, we are going to push this, we are really going to complain about this. Because we might be okay now, but there is other people coming after us.’

What advocacy model would be best?

Most interviewees felt strongly that a professional advocacy service was needed. Professional advocates were seen to have the necessary expertise and status to be effective in sorting out problems.

Peer advocacy and group advocacy were seen as less helpful models. They were seen as useful in some situations but lacking the expertise and status that a professional advocate would have. Arrangements to be made to attend group advocacy sessions are another barrier for carers. It is time consuming and expensive to travel, especially from rural areas in Pembrokeshire, and replacement care has to be organised.

‘I think a professional advocate within the hospital who is not paid by the health authority, he or she is paid by the Assembly so he or

she is totally independent from the local authorities, they can't affect his promotion, they can't affect his next pay rise, they can fight for the client all the way. It's that element no matter what model you've got, that they are independent of the system they are challenging.'

'The trouble with peer or group advocacy is that you then don't have clout, if you are trying to change things. If you've got a formal position people can't ignore you.'

'If there is an inspector of the health authority that this person is required to put in an independent report so he can raise issues with the inspector direct.'

'That's not to say that we could not maybe help people in groups as individuals, but the worrying thing about that is that you can maybe, that is something that shouldn't take the place of a formal advocacy, because with the best will in the world you might not be doing something professionally and you might end up doing damage. And advocates need to have a more important role if anything, and you can't get the respect and the power to change unless your role is seen to be of equal value to those in the statutory sector.'

'What's important is that if advocacy has to go and challenge it has automatically got a right to legal aid so that it can refer clients and judicially challenge. So that they can initiate the next step, because they must hit their heads against bureaucracy all the time. Not answering enquiries and not relying to requests. You have got to have teeth. We would like a legal budget put there for legal aid, which the advocate can use to go to the High Court for an order to the local authority saying, you will produce, you will comply. It is insurance, it might not be needed. The ability to go right to the local assembly. The right to appeal to those who are elected, the right to appeal to those that administer the law. Because of human rights, the legislation is already there, so what happens to our human rights if bureaucracy plays its game. And we are not then people, we are just figures.'

Group advocacy also raised concerns over confidentiality:

'I wouldn't like a group, because you've got a lot of personal issues that you wouldn't even want to, if it was your DLA, you wouldn't want everybody to know that you are on income support. I actually don't like group things like that. I don't like carers meetings. Even then I felt vulnerable. In the beginning you were told everything was confidential. But I didn't trust to talk freely about my feelings,

because I had an experience another time. Somebody said something to me that they'd obviously been told from this carers meeting, and I was furious. So I don't really like group things. It might be a good idea for some people. If it was something personal I'd prefer a one-to-one with someone dealing with it.'

Many interviewees made it clear that they would only use an advocacy service for a really serious problem, and that they would try their best before asking for help.

'I think to have an advocate, someone to speak for you, you'd have to have a fairly big problem. I don't think I would ask for help, I would try myself first. It would have to be something quite serious I think to involve someone like that. And yet, it's needed in lots of things. I don't think I would use one at the present, because I think I'm clued up a bit, I would fight myself. To a certain degree. And then you go on, and you give up. And then you would go on to something like that. But I'm sure there are many people who are not in my position, so many living alone, with no family around. At the moment I don't think I would use it, but the day may come tomorrow.'

Focus group discussions

Three focus group discussions were held as part of meetings of carers support groups. The research was first introduced and an explanation of advocacy was given. This was followed by a general discussion of advocacy and whether and how this could help carers. The following themes were expressed in those discussions:

- General support for an advocacy service for carers. Concerns were raised that often surveys and research is carried out with no real outcome that benefits carers.
- Advocacy service should be a one-stop-shop: linked to other carers' services and support.
- An advocacy service should make sure to access the different groups of carers and to offer the expertise required (carers of different ages and different ages of cared-for people, carers of different groups: people with learning, physical and sensory disabilities, mental health problems)
- Advocacy support should be offered at the beginning of the caring role, e.g. birth of a child with special needs, diagnosis or hospital discharge of relative
- Professional independent advocacy: an advocacy service for carers should be run professionally to ensure the best expertise in carers' issues. It was also emphasised that advocates should be appropriately trained and supervised
- A service should include young carers. Peer advocacy might be especially useful for young carers and young adult carers
- An issue of concern that an advocacy service for carers should address is the benefit system, help with filling forms, understanding the system and campaigning for increased amounts of money going to carers
- Advocacy should address supporting carers who wish to return to work (or not) depending on their particular caring role
- An advocacy service should be an independent service in the community with its own office or situated in a local voluntary agency with carer-related experience or the local Citizens Advice Bureau
- An advocacy service should be publicised via both statutory and voluntary groups, the internet, local radio and the local press

Advocacy services for carers outside of Pembrokeshire

Wales

Bridgend Carers Centre Advocacy for Carers

Aim: To provide a one to one support mechanism for carers of all ages and to develop a range of opportunities to work with carers on an individual basis to enable them to identify their own needs.

Model: Professional advocacy

Funding: A pilot scheme funded through the Carers' Special Grant, budget £15K for one part-time worker

Hafal Mental Health Cardiff Carers Advocacy project

Aim: Hafal sees advocacy as a way of empowering people. It helps you express your personal views and needs so that you can get your rights and entitlements. Advocacy assists people to make informed choices by offering the information required. For carers of people with mental health problems.

Model: Professional advocacy, plus Support Groups and service development

Workload: helped 203 carers in 2006/2007

The UK

Lothian VOCAL Carers Centre Advocacy Service

Aim: ... that by listening and understanding we can work in partnership with carers to empower and support them in their endeavours to find the best possible outcome to their situation.

Model: Volunteer advocacy using carers. One full-time manager and 11 trained volunteer advocates.

Funding: Started in 1997 with a three-year Lottery Board grant of £64K, the first of its kind in Scotland. Currently VOCAL receives £34K funding from NHS Lothian and £10K from Midlothian Council.

Workload: 60 cases per year - exceeding funding targets. The service has got a waiting list and currently hasn't got the capacity to provide crisis advocacy (at short notice)

Hampshire Carers Together Carers Advocacy Service

Aim: Advocacy within Carers Together aims to ensure that individual carers have a voice and are listened to. Advocacy is about enabling carers to feel equal and empowering them to speak up for themselves. Advocacy within Carers Together is about helping carers to tackle a single issue with which they need help, support or information. Advocacy is about representing carers' expressed wishes and acting under their instruction. Advocacy within Carers Together aims to ensure that carers are able to make informed choices based on unbiased information.

Model: Part-time advocacy co-ordinator working with a small number of trained volunteers

Carers Association in South Tyneside Carers Advocacy Service

Aim: To provide a free and confidential advocacy service for adult carers of adults

Recommendations

The research shows clearly that carers in Pembrokeshire do see a need for a professional advocacy service dedicated to carers. The following recommendations detail what such a service should look like to be beneficial to carers.

- An advocacy service which is accessible for all carers should be established in Pembrokeshire.
- The advocacy service should be a 'one stop shop' where carers can get a complete range of information on support and benefits that are available. Any new advocacy scheme should link in with existing carers support services.
- Advocacy should act as early as possible, ideally from the very start of the caring role, to support carers when they need it and to prevent conflicts.
- The advocacy service should be an independent and professional service ensuring expertise, status, appropriate training and supervision of the advocates, as well as confidentiality. To ensure this, any newly established advocacy scheme should follow the Action for Advocacy Charter.
- An advocacy service should make sure to access the different groups of carers and to offer the expertise required (carers of different ages, carers of different groups: children, adults and older people with learning, physical and sensory disabilities, mental health problems).
- An advocacy service should be accessible for carers from all locations in Pembrokeshire.
- An advocacy service should include young carers and/or work closely together with existing services for young carers.
- An advocacy service should work in a flexible way to meet the needs of carers.

Appendix

Research Project – Advocacy for Carers in Pembrokeshire

An advocate is

- Someone who helps you to make **YOUR** voice heard
 - Someone who works under **YOUR** instructions
 - Someone who is on **YOUR** side at a difficult meeting
- Someone who helps **YOU** to find the information you need
 - Someone who listens to what **YOU** want to achieve
 - Someone who helps you to work out **YOUR** choices⁵
 - Someone who treats all information in confidence

It is estimated that there are approximately 15,000 carers in Pembrokeshire, many of whom need support/advocacy at times of major decision making or difficulties. In Pembrokeshire's Carers Strategy Action Plan, one of the action points is 'to develop advocacy support systems for carers'. There is no dedicated advocacy service for carers in Pembrokeshire, and there is concern that the advocacy services available to carers at the moment are not sufficient and not specific enough. The research aims to establish what services are available at the moment, where the gaps are and what new or extended services should be provided.

All information you give in the interview will be treated in confidence. The recording will only be used to help with note taking and will be destroyed at the end of the project.

Many thanks for your help.

If you have any questions please contact:

Bettina Becker
PAVS, Pembrokeshire Association of Voluntary Services
36-38 High Street
Haverfordwest
SA61 2DA

Telephone 01437 769422

Email: Bettina.Becker@pavs.org.uk

⁵ We thank Carers Together Hampshire for being able to use this summary of advocacy.

Advocacy for carers

We are looking into the need for an advocacy service for carers in Pembrokeshire and we would like to get your views. We would appreciate if you could fill in this questionnaire and send it back in the enclosed freepost envelope. You can fill in the form anonymously or give us your contact details, if you wish.

An advocate is

- **Someone who helps you to make YOUR voice heard**
 - **Someone who works under YOUR instructions**
 - **Someone who is on YOUR side at a difficult meeting**
- **Someone who helps YOU to find the information you need**
 - **Someone who listens to what YOU want to achieve**
 - **Someone who helps you to work out YOUR choices⁶**
 - **Someone who treats all information in confidence**

1. Have you ever had the support of an advocate?

Yes No

If yes, what organisation provided the advocacy service?

What was the issue the advocate helped to address?

How helpful was the advocate in resolving the issue?

Very much 1 2 3 4 5 Not at all

2. Have you as a carer ever felt you needed an advocate, as described above?

Yes No

If yes, in what situation?

⁶ We thank Carers Together Hampshire for being able to use this summary of advocacy.

3. What services do you use that support you in your caring role?

4. Which of these descriptions most closely describe the person / persons you care for?

- Children Older person
 Adult with a physical disability Adult with a mental health problem
 Adult with a learning disability

5. How old is the person / are the persons you care for?

- Under 18 18 – 24 25 - 49 50 - 64 65 - 84 85+

6. About you (please give us your contact details if you are happy for us to contact you about this research)

Name _____

Address _____

Telephone _____ Email _____

I am a current carer I am a former carer

What is your age?

- Under 18 18 – 24 25 - 49 50 - 64 65 - 84 85+

7. Can we contact you about this research? Yes No

Thank you.

Please return this questionnaire by the **31st of May 2008** in the enclosed envelope to:

Bettina Becker
FREEPOST SWC4881
36/40 High Street
Haverfordwest
Pembrokeshire
SA61 2ZZ

Please contact Bettina Becker on 01437 769422 if you have any questions about the research.

Advocacy for carers in Pembrokeshire

Interview guide

Introduce project and explain what advocacy is, give examples of informal advocacy:

An advocate is

- Someone who helps you to make **YOUR** voice heard
 - Someone who works under **YOUR** instructions
 - Someone who is on **YOUR** side at a difficult meeting
- Someone who helps **YOU** to find the information you need
 - Someone who listens to what **YOU** want to achieve
 - Someone who helps you to work out **YOUR** choices⁷
 - Someone who treats all information in confidence

Explain use of digital recorder and assure confidentiality. Recordings are only used to help note taking and are deleted at the end of the project.

1. Can you please tell me a little bit about yourself and the person you care for?
(Age, gender, health problem, for how long the caring relationship has existed...)
2. What support do you get at the moment for the person you care for and for yourself?
(How did you find out about the support and how did you access it?)
3. Can you describe a situation when you needed support or help?
4. Do you think an advocacy service could have helped you?
5. How should such a service operate and where should it be based?
(Discuss professional advocacy, peer advocacy, group advocacy...)

⁷ We thank Carers Together Hampshire for being able to use this summary of advocacy.

Advocacy for carers in Pembrokeshire

Guide for focus group sessions

Introduce project and explain what advocacy is, give examples of informal advocacy:

An advocate is

- **Someone who helps you to make YOUR voice heard**
 - **Someone who works under YOUR instructions**
 - **Someone who is on YOUR side at a difficult meeting**
- **Someone who helps YOU to find the information you need**
 - **Someone who listens to what YOU want to achieve**
 - **Someone who helps you to work out YOUR choices⁸**
 - **Someone who treats all information in confidence**

Explain use of digital recorder and assure confidentiality. Recordings are only used to help note taking and are deleted at the end of the project.

6. Introductions: Can you please say a little bit about yourself and the person you care for?
7. Can you describe a situation when you needed support or help? Do you think an advocacy service could have helped you then?
8. What model of advocacy would be most useful (explain professional advocacy, peer advocacy, group advocacy...)
9. How should an advocacy service operate and where should it be based? How should it be publicised?

⁸ We thank Carers Together Hampshire for being able to use this summary of advocacy.