

**Report on Care-Planning Priorities, Self-Management
Issues and Service Needs,
for consumers with Chronic Fatigue Syndromes:
a pilot study conducted in the
Southern and Hills districts of Adelaide.
June-December 2002**

**Working Paper 4:
Complex Chronic Illness Primary Care Best Practice Research &
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This Focus Group Report was an initiative of many stakeholders in South Australia who work for people with the Chronic Fatigue Syndrome ME/CFS group of illnesses and related overlapping disorders to improve their management and access to services.

The Participants; People with the Chronic Fatigue Syndrome group of disorders, their Carers, families and support people

Staff at the local Health Centres and Divisions of General Practice

Individual General Practitioners and other providers in the local areas.

Fibromyalgia SA

Mitcham City Council

Onkaparinga City Council

Victor Harbor City Council

Mt Barker and Adelaide Hills Councils

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EXECUTIVE SUMMARY

The lack of information on General Practice interventions, other health, community and support services has prevented people with the Chronic Fatigue Syndromes (ME/CFS, CFS/ME, Myalgic Encephalomyelitis) group of medical conditions participating in Australian Government service improvement initiatives. This study was conducted to identify the current medical and support services used and the policy gaps for this group of clients (Home and Community Care, 2002; Enhanced Primary Care, 1999; Chronic Disease Self Management (Department of Health and Ageing, 1999-2003), South Australian Department of Human Services, 2001).

This, the resulting pilot study conducted in the Southern and Hills districts of Adelaide has revealed:

1. these clients, people with Chronic Fatigue Syndromes (CFS) and associated disabilities, are not participating in outcome focussed General Practice care planning / coordinated care, or chronic disease management approaches to health and community service delivery
2. that participants in this study were not aware of the services available in the community that could help them to improve their health status or quality of life
3. that participants were not able to access or were excluded because they did not meet the assessment criteria for health, home and community care (HACC) and disability support services available for such clients, particularly when compared with those currently available to other Australians with comparable levels of disability and complex care needs
4. a worrying loss of confidence in General Practice, and other health and community services
5. inconsistent or the lack of up-to-date or information circulating in the community is misleading both consumers and providers and thus influences short and long-term health outcomes

6. participants had realistic expectations, much of the serious shortfall in service provision revealed by our study being remediable if people with CFS were to gain equitable access to Federal, State and Local Government funding and services
7. an urgent need for provider and consumer education on how '*outcome-focussed service delivery*' and '*Chronic Disease Self Management*' frameworks (Department of Health and Ageing, 2000) can address many of the generic care needs and service problems of Australians with long term medical conditions, including poorly understood disorders such as the Chronic Fatigue Syndrome group.

The study's conclusions include a recommendation that extending the Federal Department of Health and Ageing Initiatives of Enhanced Primary Care, Chronic Disease Self-Management programs designated for '*all Australians with complex chronic conditions*' (EPC, 2000) to people with poorly understood complex chronic illnesses such as the Chronic Fatigue Syndrome group will:

1. improve their health outcomes and reduce their associated levels of disability
2. facilitate early intervention and preventative care and reduce loss of confidence in health services
3. prevent loss of income / work and long term dependence on the health and welfare system
4. reduce the burden of CFS on individuals, families and the Australian community
5. reduce the currently unacceptable delays between research and clinical practice and facilitate the provision of current best practice community care not yet available to these clients (Couper MJA, 2001; Community Consultation Submissions to Australian CFS Clinical Guidelines, 1996 & 2002)
6. provide a cost-effective equitable solution to the ethical dilemmas and service and information quandaries associated with poorly understood chronic disorders known as Chronic Fatigue Syndromes (Myalgic Encephalomyelitis, ME/CFS) in the Australian community

7. facilitate an ongoing systematic data collection process based on patient health outcomes and appropriate health and community service interventions for this client group.

Such an extension of the relevant programs to this patient group would provide a cost-effective, realistic path towards service improvement, moving from current best practice to evidence based care while concurrently addressing the immediate needs of patients currently ill-served by community and disability support services and the medical profession.

Unintended outcomes of this study have been even more instructive than our now systematically assembled baseline data for care, service planning and CareLink type community information database evidence.

In particular we found unexpected high levels of disability in the study sample (80% were housebound and 76% were not registered at local health and support services), and an almost total unawareness among CFS patients of the currently available health interventions and services and community support programs available in their local community.

For sufferers, their determination was their desire for 'normality', their priorities were environmental and community access issues which other people take for granted as part of everyday life. They repeatedly raised the subject of lack of acceptance of their different and multiple chemical reactions and how these excluded them from participating in every day activities (shopping, eating out, socialising etc.) and their difficulties in finding suitable accommodation / housing.

Despite their high levels of disability and social isolation, participants in this study did not have access to prevention and rehabilitation services or any planned strategies to limit the impact of their illnesses or to work with General Practitioners or other providers to improve their health care / outcomes. The services they used were ad hoc because they advised they had been refused care and had lost confidence in both health and community support services for long-term and/or permanently disabling illnesses such as their own.

Moreover, contact with service planners and providers during the research process revealed a similar lack of knowledge (a) of the extent of Chronic Fatigue Syndromes in the community and (b) of the associated range and levels of neurological and physical disability, which currently affect over 150,000 Australians.

Participants identified some services or medications that had helped them but advised that in the six months prior to the study they had not been able to afford them.

Incidentally, clients interviewed demonstrated a consistent readiness to be involved and to re-think their situations and to continue participation in 'shared' management and chronic disease self-management educational programs beyond the initial contacts made.

We therefore present this pilot-study as:

1. the first step towards a long overdue examination of the medical care, health and community and disability support needs of the many tens of thousands of Australians who currently suffer from the Chronic Fatigue Syndrome (CFS) group of disorders
2. justifying advocating the extension of outcome focussed care to Australian CFS sufferers through the Federal, State and Local Government-based health, disability and community support programs, funding and services currently available to persons with comparably disabling conditions (e.g. arthritis, diabetes, heart, respiratory, osteoporosis and co-morbid depression) under the 'Enhanced Primary Care Initiative' and 'Chronic Disease Self-Management' Initiatives'
3. we also propose that extending the use of the focus group and telephone structured interview methodology of data collection to people with CFS in other geographical areas across Australia to address the current paucity of information. This would provide a cost-effective method of information gathering to move from the current anecdotal to systematically gathered information. The ongoing lack of such information continues to compound the situation for people with CFS because it excludes them from Australian (Federal and State) policy, program and service planning initiatives.

The extension of Government programs cited would be cost-effective because it would facilitate inclusion, early intervention, prevention and rehabilitation in the early stages of

the CFS illnesses processes. As CFS is mostly a non-progressive and non-degenerative disorder this would reduce much of the need for long-term home and community care (HACC) services. This would limit the poor health outcomes, unnecessary loss of work / income and increased levels of disability cited by our respondents, that they directly related to inappropriate treatments / interventions available in the community.

The resulting information will be available through community service databases and for General practice care planning to enable this group of Australians to have equitable access to services in health and community service programs and current best practice health care that still eludes them.

1. INTRODUCTION TO THE PILOT NEEDS /SERVICE PRIORITIES PROJECT

This report details the findings of service needs research on people with Chronic Fatigue Syndromes (CFS) in the Southern and Hills Districts of Adelaide conducted during the six month period, June to December 2002.

The study was prompted by problems hindering daily care and the participation of Chronic Fatigue Syndrome patients in health and community services (including Home and Community Care (HACC), General Practice Enhanced Primary Care (EPC), Chronic Disease Self Management (CDSM) Programs (Department of Health and Ageing, 1999-2003; South Australian Department of Human Services, 2000).

It had been found that the inadequacy of data on the medical, health and community support services currently used by people with 'CFS' further excluded them from benefiting under individual care planning and service development initiatives.

While it is estimated that over 150 000* Australians are affected by 'CFS' (*0.2-0.7% of the Australian population cited in the Australian CFS Clinical Guidelines Royal Australian College of Physicians, 2002), health and community service records do not identify people with CFS as a client group or provide information on the services they use.

The service needs project is a *'pilot study'* aimed at reaching and gathering information from people with 'CFS' representative of the 'real needs' of CFS consumers in the sample community (Southern and Hills Districts).

Chronic Fatigue Syndrome 'a descriptive term'

Chronic Fatigue Syndrome (CFS) also known as Myalgic Encephalomyelitis or ME/CFS (ME/CFS Association of Australia, 2002) or CFS/ME (Oxford Concise Medical Dictionary, 2002) is a group of poorly understood acquired complex chronic disorders with numerous symptoms indicative of brain, immune and endocrine systems dysfunction (ME/CFS Association of Australia, 2002). The Australian Chronic Fatigue Syndrome Clinical Practice Guidelines (RACP, 2002 S23) state that Chronic Fatigue Syndrome, CFS, is a descriptive term used to define (or group) a pattern of symptoms that cannot be attributed to any alternative condition. There exists no documentation on the levels of CFS, the associated disabilities or on the current health management

strategies or services used by people with CFS-induced disabilities in the Australian community.

For this 6-month study conducted in South Australia, the term '**Chronic Fatigue Syndrome**' or '**CFS**' was used. This study aimed to reach and gather data from people in the community who had or identified with the complex syndrome disorder of Chronic Fatigue Syndrome (CFS) sometimes called ME/CFS or CFS/ME. All participants had received a diagnosis of Chronic Fatigue Syndrome (CFS) from a medical practitioner and identified with the CFS client group. Chronic Fatigue Syndrome, CFS, is the overarching term; the name most recognised by consumers and providers in the wider community in South Australia.

Lack of records hinders people with CFS being included in service planning

As stated above, as of the date of this report (December 2002) there had been no large-scale community based study on people with CFS (Chronic Fatigue Syndrome) in the Australian community (RACP, 2002, S28). As a result there is a lack of firm information on the numbers in the community, their distribution, the natural history of the illness and associated levels of disability.

Despite the Government funded Australian CFS Guidelines (RACP, 2002) documenting estimates of the prevalence of CFS as high as 2.5% in primary care service settings there is still no systematic collection of data on the use of community and allied health services or medical interventions by people with CFS.

This lack of records further disadvantages people with CFS because for General Practitioners and other providers wishing to include them in care planning / service co-ordination activities (Department of Health and Ageing, 1999) no information is available on appropriate services or their availability. Health and community service providers are unable to categorise CFS according to the established medical or service delivery models / disability classifications / service access criteria assessments. For policy and service planners this means a lack of data on the numbers of people with CFS attending General Practice, specialists, and other providers and on current treatments and interventions used by sufferers as well as on service needs or gaps. This compounds an already bad situation as it further excludes people with CFS from allied health and

community services, programs, planning and funding (see Section 2. Background to service and care needs of people with CFS).

Project Goal

The goal of the project was to gather information from people with the Chronic Fatigue Syndrome (CFS) group of illnesses within a sample geographic or local government area (Southern and Hills Districts of Adelaide) that would indicate a) the situations and current needs of 'CFS' consumers in that community and b) the extent to which better community service planning and coordination could assist in meeting those needs.

Researchers Note: The original project design planned to use focus groups with a structured interview format as the research methodology, but during the research process this had to be extended to telephone interviews using the same structured interview format because many of the people with CFS who responded to the advertisements were unable to attend group activities because of their poor levels of health and disability.

Focus Groups: a strategy to gather new and representative information

The focus groups were held as a cost efficient strategy to gather baseline information (qualitative and quantitative) on the current situation, service usage and gaps and so address the paucity of data on people with CFS currently available at the General Practice, local government and community service levels.

Australian community services are largely funded in accordance with the available local government records and data on the needs and priorities of residents (Home and Community Care (HACC) funding priorities). Hence, as a preliminary to improving patient access to services the data gathered should be 'representative' information on people with CFS 1) to support / inform individual patient care management and 2) to demonstrate the need for community service planning and appropriate system level funding.

Service needs and priorities: a pilot study

This series of structured interviews is a 'pilot study' because it evaluates the 'data collection process' and the use of focus groups / telephone interviews as an appropriate

and cost-effective method of expediting the collection of data from people with CFS in their local communities enabling representative assessments to be made of consumer or client group needs in typical local service districts.

The focus group / telephone interview method of data collection was chosen because other data collection methods had failed. Preliminary information gathering, including record searches and written questionnaires distributed nationally through consumer groups (National Consumer Group Survey 2001-2002) could not (1) confirm service usage and (2) failed to tally with estimates of CFS patient / client totals in the community as suggested by the research literature (RACP, 2002). While many agencies including General Practitioners provided anecdotal evidence on service problem issues at the community service interface level, service access records obtainable from community databases and information centres failed to record services used by people with CFS (communications by project staff with service agencies).

Hence, the focus group / telephone interview project was implemented as a strategy to gather data and break the ongoing cycle of lack of information problems. The focus groups held in local community centres in the sample geographical area aimed to provide a forum for people to meet face to face with the researchers to provide their information on service needs / gaps.

This study used structured interviews administered during focus groups / phone interviews as a research methodology to:

1. facilitate / enable participation by a maximum number and variety of persons affected by CFS, their carers and providers in sample local communities
2. gather new service needs information aimed at enhancing understanding of the CFS illness experience in their local community (Australian community services largely being funded at the local level)
3. gather up-to-date information applicable to future care planning, self management training programs and to help people access the full range of services to help them in relation to:
 - 3.1 services and interventions available to people with CFS
 - 3.2 reliable information for local community service providers

4. explore current General Practitioner, other health interventions and services used
5. increase understanding the CFS 'illness experience' in the community
6. deliver useful / usable information to providers, community 'CareLink' type databases and policy and program service providers / planners.

2. BACKGROUND TO SERVICE AND CARE NEEDS OF PEOPLE WITH CHRONIC FATIGUE SYNDROMES (CFS).

As described above, this study is a solution-focused initiative to improve the health management and service access for Australians with the Chronic Fatigue Syndrome group of illnesses (CFS).

This study was conducted specifically to gather data from people (health consumers) with Chronic Fatigue Syndromes and to explore information gaps and thereby support Australian Federal, State and Local Government service improvement initiatives.

The purpose of the current series of consumer consultations

In 1999 when the Department of Health and Ageing's Enhanced Primary Care and Chronic Disease Self Management Programs were first implemented for people with chronic illnesses in the Australian community, the lack of data (Federal, State, Local Government) on people with the Chronic Fatigue Syndromes meant that it was difficult to include 'CFS' in the wider moves to improve care and health management for people with long term medical conditions.

In 2002, the Federally funded Australian Chronic Fatigue Syndrome Clinical Guidelines recommended that 'care planning' was appropriate for people with CFS.

'Doctors may need to co-ordinate the help of other healthcare and education professionals...' (Australian CFS Guidelines MJA.S26, May 2002)

A realistic and cost-effective way of bridging the gap between the research literature and daily clinical practice would be achieved by providing CFS sufferers with equal access to the Enhanced Primary Care / Chronic Disease Management Program Initiatives (EPC, 2000). This would provide them with General Practice 'holistic multidisciplinary care planning' monitored according to outcomes, as well as an integrated approach to service delivery with the '*right mix of services at the right time*' and with '*a greater role in decision making about their health*' (Department of Health and Ageing, 1999). The EPC initiatives also include improving community access to information about chronic conditions and about the health system and community services (Commonwealth CareLink Program 2002).

Chronic Fatigue Syndrome, CFS, is a long-term medical condition (see Appendix 1 Consumer Group Information) with no known cure and no evidence based medical interventions or consistent information on the natural history or management of CFS in Australian General Practice settings. Sufferers report that this lack of information means that they do not have access to consistent medical treatment, are often misunderstood and displaced, and have difficulty accessing available health and community services.

A 1988 consumer survey of people living with Chronic Fatigue Syndrome (ME/CFS) conducted in South Australia (Powell, 1999) found that consumers' experience of services and / or failure to access care were compounding factors in their illness and influenced their associated high levels of disability. Other Australian studies, Woodward, 1992, Holloway and Pinikahana, 1998 and Bartlett et al, 2002, have reported similar findings.

General Practitioners providing care for people with CFS have confirmed that the lack of such consistent information on current interventions is a factor that significantly limits care for people with CFS (General Practitioners CPD Evaluation, 12.2001).

Accordingly, the ME/CFS Primary Care Best Practice Research and Evaluation Project (see Appendix 2) has proposed that including the *Chronic Fatigue Syndrome group of disorders in Enhanced Primary Care, Chronic Disease Self-Management Program activities (1999–2004) will provide a cost-effective process towards reducing the burden of CFS on individuals, their families and the Australian community.* This proposal accepts the Governments' program hypothesis that providing General Practice 'holistic multidisciplinary care planning' and 'access to a range of appropriate and timely services' for sufferers of complex chronic conditions (EPC, 2000) will improve their health outcomes and quality of life, and reduce the associated disabilities and compounding social and loss of income factors (EPC, 2000).

Appropriate service provision for people with CFS requires that they gain immediate access to appropriate and timely services and General Practice care planning as well as appropriate self-management activities. This strategy would enable their inclusion in national and state program outcome evaluation statistics and on to community databases that inform policy, service and program development priorities as well as also increasing understand of CFS in the community.

This report documents information gathered from informants using a *structured interview format* in focus groups and telephone interviews. The information was provided by people with CFS about their use of services and interventions. It also lists problems and themes that respondents identified as affecting their health status as it related to living with CFS in their local communities.

The structured interview questions.

A structured interview format was used to standardise the data gathering process. To enable current and relevant information on service needs the study questions defined a specific time frame of the immediate 6-months prior to the focus groups (January to June 2002).

The questions were developed from questions in sample / model care plans obtained from '*Model Guidelines for the Management of Chronic Conditions*' (Appendix 4 Royal College of General Practitioner (Western Australia, June 2002).

Four main questions were used:

1. *What were the things that have affected your health and quality of life in the last 6-months?*
 - a. *What has made it worse?*
 - b. *What improved your health?*
2. *During the next 6-months what would you like to do to improve your health?*
3. *How can you do this?*
4. *What services do you need to help you?* (see Appendix 3)

The questions were administered after an explanation of the purpose of the information to be provided / collected. After piloting, the wording was carefully chosen to make the questions clearer to participants with CFS cognitive problems. The questions still proved a challenge to respondents because most were overwhelmed by their ill health and living challenges, had given up on trying to get help and services and had placed limitations on their expectations and activities in order to survive daily living.

3. AIMS OF THE SERVICES NEEDS /PRIORITIES STUDY

1. To gather service usage and needs information from people with Chronic Fatigue Syndrome (CFS) in their local community (Southern and Hills districts of Adelaide).
2. To facilitate / enable participation by a maximum number and variety of persons affected by CFS, their carers and providers in the local community.
3. To gather up-to-date information applicable to future care planning, self management training programs and to help people access the full range of services to help them in relation to
 - 3.1 services and interventions available to people with CFS
 - 3.2 reliable information for local community service providers.
4. To explore current General Practitioner, other health interventions and services to increase understanding of the CFS 'illness experience' in the community
5. To circulate useful / usable information to providers, community databases and policy and program service providers / planners.
6. To pilot the use of structured interviews administered via focus groups and telephone interviews as a cost-effective research methodology to gather representative information on the needs, management strategies and services used by people living with the Chronic Fatigue Syndrome (CFS) group of illnesses.
7. To develop a Focus Group / Telephone Interview Kit for use in other local government areas.

4. OBJECTIVES OF THE PROJECT

To conduct a project, using students (Social and Behavioural Science) from Flinders University as independent and unbiased researchers.

To gather information from sufferers of the Chronic Fatigue Syndrome (CFS) group illnesses in the Southern and Hills Districts of Adelaide using focus groups / telephone interviews to

1. gather current and useful service improvement / needs data suitable for multidisciplinary care planning from people with CFS
2. gather new service needs information aimed at enhancing understanding of the CFS illness experience in their local community (Australian community services largely being funded at the local level)
3. develop lists of service data for use in health and community service provision / access.

Also to

4. reach out and contact people with CFS using local community networks, advertising, notice boards, agencies (strategy to obtain an unbiased and representative sample)
5. facilitate participation of a representative sample of people with CFS in the local community
6. facilitate participation of the range of associated disabilities and severity of people with CFS.

5. ANTICIPATED OUTCOMES

1. Information on the numbers and typical needs of people living with the Chronic Fatigue Syndrome group of illnesses in the Southern and Hills Districts of Adelaide South Australia, plus data on the management strategies and services currently used by patients (useful for both individual patients cares and systemic service planning).
2. Improved participation of people with CFS in available primary care services including Chronic Disease Self-Management (CDSM) Activities.
3. Up-to-date information on services for people with CFS available for community databases, General Practice multidisciplinary care planning, community services and future CDSM activities.
4. Information for CFS management available for community databases, including CareLink Information Centres, General Practitioners and other providers.
5. Information on problems related to surveying people with CFS in their local communities.
6. Study implementation package available for wider use across Australia that includes
 - 6.1. Information on conducting Focus Groups / telephone interviews to gather information from people with CFS
 - 6.2. Information for Study Group Leaders
 - 6.3. Information for Study Participants.
7. An ongoing strategy to gather baseline data to support service improvement processes for sufferers of Chronic Fatigue Syndromes moving from current best practice to evidence based care.

6. RESULTS: SECTION ONE

Reaching people with Chronic Fatigue Syndrome in their local community

As described above, these focus groups / telephone interviews held during June - December 2002 in the Southern and Hills Districts of Adelaide South Australia, aimed to gather service usage and needs information from people with the Chronic Fatigue Syndrome (CFS) group of disorders. This included designing a methodology that enabled participation by a maximum number and variety of persons affected by CFS in the local community.

Study sample representative of people with CFS in local community

To achieve the study goal, data / information needed to be collected from a sample of **people living with CFS in their local community that is representative of consumer-specific needs.**

Reaching people with CFS in the Southern and Hills Districts of South Australia proved a challenge because they are not a recognised client group for service agencies.

During the six months of this study (June – December 2002), one hundred and nine (109) people with CFS in the Southern and Hills Districts of Adelaide South Australia provided information on their current and potential use of health interventions and community services, and their recent 'lived experiences'.

The 109 participants reached in the 6-month timeframe are not presented as the total of all CFS consumers in the area, but as a **representative sample of self-selected people with CFS in the Southern and Hills Districts of Adelaide South Australia** (see below *Limitations in sample size*).

Most importantly for medical, health and community services, data gathered by this study includes **information from those at the 'severe' end of the CFS associated disabilities. Eighty (80%) percent of respondents were housebound during the time of this study** (see below *Limitations time needed to facilitate participation...*).

People with CFS are difficult to reach via community networks

This study found that most people with CFS (76% of sample) were 'hidden'. They are not registered at community support services or health centres and could not be reached through the usual health and community service networks / records / advertising. Furthermore they could not be reached through consumer group networks, 104 of the total 109 (95%) were not members of the state Chronic Fatigue Syndrome consumer group.

Breakdown of the successful contact methods to reach the 109 people with CFS

- 24% (26) participants were reached via providers including
 - letters to Divisions of General Practice and General Practice clinics
 - letters / flyers to individual providers and local health centres.
- 76% (83) were reached via other means including:
 - advertisements in local newspapers
 - notices on community and shopping centre notice boards
 - promotional leaflets left in local health and Community Centres.

Limitations in sample size

The final sample size is influenced by

- 1) the time needed to locate and recruit people with CFS in their local communities and then
- 2) to facilitate group attendance or telephone interviews within the 6-month timeframe (June to December 2002) of the study.

Difficulties were not only (1) locating people with CFS, but also (2) facilitating the data collection at times suitable for their individual health and disability limitations and (3) restoring confidence in service provision / improvements.

The short timeframe of six months, June – December 2002 of the study exerted limitations on

- (1) the number of participants reached
- (2) the time needed to facilitate participation of the people with CFS contacted (severity of CFS in sample)
- (3) the volume and quality of the information gathered.

At the time of writing, new CFS contacts are still ringing the office to answer the advertisements with requests to participate. People are advising they kept the advertisement to think about the request for information or to call when they were feeling better or needed help.

To limit the problems arising and to maximise participation the data collection activities needed to be flexible. Extending the opportunities to more effectively reach the numbers of people with CFS and allowing them to provide information via phone interviews at times suitable for respondents facilitated input from the spectrum of the illness and associated levels of disability. (See below *The time needed to facilitate the participation of the people with CFS contacted*)

Limitations in sample size vs. range of community networks

One hundred and nine (109) people with CFS were contacted during the six months period of the study via a variety of local community networks and advertisements. These people responded to repeated publicity sent to local health and community providers, community notice boards and local newspapers.

The first responses were slow. To gather data from as many people with CFS as possible multiple methods of advertising / promotion were used and repeated at weekly intervals.

The original recruitment period of 6 of the 26 weeks of the study had to be extended because people with CFS, family members and carers continued to contact the office wanting to provide their information on service needs / experiences.

During the recruitment stage of the study, letters were sent to health centres advising them of the focus group study and its goals. Staff expressed support for the work and

offered suggestions on how to contact people with CFS in their region. In return, community service staff requested copies of the study findings.

The range of community network methods used to distribute publicity should also limit potential bias in the final participant sample.

The resulting sample group includes a **spectrum of people with CFS** i.e. those who already access services, others who did not attend services and a third group who travel to other areas for service needs. The extra time to include sufferers from the **severe / high level of disability** was considered important in regards to their potential use of home and community services.

Advertising to reach people with CFS within the timeframe

It was found that people with CFS often did not read local papers, go to local shopping centres to see notice boards, attend community services and or participate in wider community activities.

Most participants recruited reported that they or a friend had stumbled across the advertisements by chance rather than via seeking information on activities for people with CFS. New participants continued to call after data gathering was complete, suggesting that if more time had been available a larger sample of consumers could have been contacted.

Newspaper advertisements needed to be repeated at least three times. Responses to flyers left in health services, notices on shopping centres and other community centre notice boards tended to be much delayed.

As described in the 'breakdown of successful contact methods' respondents were reached by all of the promotional methods used and all were important as no one method could be identified as effective for people with CFS, their families or carers.

The time needed to facilitate participation of the people with CFS contacted.

Most of the 109 respondents were not well enough to attend a group activity such as a focus group in their local area. Some advised that they did not leave their home or local community but at the same time insisted that they wanted an opportunity to participate and provide information.

In discussing facilitating the participation of people with CFS, the importance of the initial contact must be identified. People with CFS would call to ask for more information. Project staff spent time answering questions and to reassure callers that their contribution was important, valued and that the information they provided would not be used against them in future service requests.

The severity of the health and physical disability limitations encountered was unexpected. This included both illness severity and poor or nil mobility within the community.

To maximise participation and to accommodate special needs, data gathering was extended beyond the focus group activities. This was achieved via the pre-booked phone interviews, and through providing feedback sheets that allowed people to provide additional information in written format.

The resulting information was thus gathered via a combination of methods tailored to individual needs, i.e. data gathering was more complex and time consuming than initially anticipated. Eighty-eight respondents provided information through pre-booked telephone interviews.

Three focus groups were held at Victor Harbor (Victor Harbor City and Alexandrina Council Areas), Aberfoyle Park (Onkaparinga Council) Blackwood (Mitcham City Council). People from the Adelaide Hills travelled to Blackwood or were reached through phone interviews.

The volume and quality of the information gathered

The volume and quality of information gathered is influenced by the respondents prior difficulties or their lack of access to services. The questions required people to provide **specific and up-to-date information on the actual services and health interventions they had used or planned to use**, see structured interview format Appendix 3.

The information required details **from the previous six months (January – June 2002)**, and **on specific services or interventions they would like to access in the next six months** as part of their General Practice care plan. To keep the group or interview focus the 6-month timeframe of the questions was strictly maintained.

Respondents found this difficult. During the interview process it soon became apparent that many respondents had very negative experiences in accessing services and that many directly related their current levels of disability to service failures.

People frequently requested time to think, as this kind of information on services was new to them. They were used to the acute care / curative approach. They found it difficult to provide up-to-date information on services that were beneficial. They had no concept of 'health management' or 'multidisciplinary care planning' approaches to care and being involved in decision making to help improve their health or quality of life. (See below *Unexpected outcomes: educational effects, community development*).

While **most required services were not medical**, respondents were generally unacquainted with planning, using community services and working with a case manager to use a range of health or community services to 1) prevent further disability or 2) limit the daily effects of their illness or 3) improve daily living and quality of life.

Unexpected outcomes: educational effects, community development for people with CFS

An unexpected outcome of this study was its educational effect in informing participants (people effected by CFS) about focusing on what is possible and about improving health outcomes through collaborative health management, multidisciplinary care planning or 'chronic disease self management' approaches to care.

The study found that the requirement to limit answers to information from a recent specific time period, stimulated peoples' thinking. It gave them a new focus on their current situations and the possibility of obtaining necessary support rather than being overwhelmed by their multiple losses of having an illness with no cure.

Respondents needed time to think about the question *'If you could choose what services, assistance or treatments would help you in the next six months?'*

Many did not have an answer during the groups or initial phone interview and asked for more time to think. Focus group participants who had had time to develop their thinking on care planning and self-management wished to provide more data. This suggests that a longer timeframe would allow more comment to be collected and reviewed.

The information provided by respondents in these one-off focus groups or telephone interviews is limited to 'wish lists' of the kind of services that might potentially help them with their CFS.

To summarise, the information provided was limited because focusing on health and service outcomes and what it is possible to change was a new way of thinking. **Care planning and sharing care / self-management for people with chronic illnesses assumes that consumers have successful provider / consumer partnerships with two-way communication designed to facilitate problem solving, shared responsibility and the monitoring of outcomes. This also includes being able meet service assessment criteria, access timely and appropriate services, understand management approaches to care with their short and long term goals.** This was **not** a reality for these sufferers of CFS. (See Results Two: *Community development / Empowerment / Provider Consumer Relationship*).

As stated, reaching out to people with CFS was time consuming, it required repeated advertising / promotions using multiple approaches via a variety of methods (community notice boards, local newspapers, flyers, word of mouth). To gather maximum responses required allowing considerable time for responses to restore and build confidence, to collect and collate the information provided. Data gathering also required accommodation of special needs and of the fluctuating health status of most of the people with CFS contacted.

7. RESULTS: SECTION TWO

Findings in relation to service provision

This section documents on the findings in relation to medical and other service provision i.e. service needs information, up-to-date information applicable to future care planning.

The information was gathered using the four question structured interview format based on General Practitioner care planning questions (Model Guidelines for the Management of Chronic Conditions, Western Australian Royal College of General Practitioners June 2002 see Appendix 4.).

Despite the timing of this project, three years after the promotion of the Enhanced Primary Care and Chronic Disease Self Management programs for people with chronic illnesses in Australia, **no respondent in this study was yet participating in any 'care planning' or 'self-management' programs.** Respondents were not aware that there were self-management activities in local centres available to them.

Participants could not identify local medical, allied health and community services that they accessed, they reported they were not eligible for services and that they had given up trying to get help through local health and community services. Only in one Local Government Area (Victor Harbor) was there a local CFS support group.

Respondents consistently reported loss of confidence in all medical, health and community support services.

People advised that they frequently did not identify themselves as having CFS to service providers because they believed that community misunderstanding of the term 'Chronic Fatigue Syndrome' leads to them being misjudged and even discriminated against.

On the other hand, service providers contacted often reported their knowledge of people with CFS but confirmed that 'Chronic Fatigue Syndrome' was not a criterion for eligibility to services.

Chronic Fatigue Syndrome sufferers' perceptions of medical care

Most participants in this study had not seen a General Practitioner (GP) or other doctor in the previous 6-months. The reasons given were that the energy expended in acquiring treatments can outweigh short term or perceived benefits, or that doctors had nothing to offer '*What do doctors have to offer?*' '*There are no treatments!*'

People perceived that because doctors did not have any medical treatments for their CFS they did not have time for them as patients and '*blamed them for making their illness up*' or for '*Illness behaviour*'. Few respondents were able to provide information on a current treatment intervention from a General Practitioner.

Sufferers frequently reported that GP's attitudes indicated that having a poorly understood or ill-defined disorder such as Chronic Fatigue Syndrome, with its resulting lack of treatments caused them to be misjudged as *having symptoms that were 'all in the head'* or inferred as being essentially psychiatric rather than organic. Respondents interpreted this as 'rejection' and were not always prepared to recognise that the lack of General Practitioner interventions and care in the community was the result of having an illness that was beyond current medical knowledge and outside community service access / client criteria.

General Practitioner care: curative or multidisciplinary care planning?

Participants still had the perception that medical care was 'curative' or for dispensing medications, many did not think that such a holistic care planning approach would work with their General Practitioner. They thought discussing anything apart from 'purely medical' matters would be inappropriate in the time limits of General Practice, or would change their current doctor / patient relationship.

While participants in the study argued that they had a long term medical condition they were at a loss or had no context to consider 'managing care', partnership type relationships and working in collaboration with a General Practitioner to co-ordinate all the services, interventions or strategies they used to limit their illness progress or improve their daily life situation. The potential of planning, focusing on what is possible, monitoring achievable targets, co-ordinating all the services / interventions they used in

collaboration with one provider was a new untested concept to them (see section Community Development / Empowerment / Provider Consumer Relationship).

General Practitioner care: limited access, perceived relationships

Most participants could not identify a General Practitioner or other medical provider whom they felt understood the complex nature of their long-term medical condition. Few could identify a provider that they had found willing to work with them to limit the impact of their illness (see Results Section Three: *Services Planning Matters and Current Service Lists*). This was the reason they placed great importance on 'information for doctors'. See *Results: Section Three Standardised Information Access: available, reliable and up-to-date*. It also meant that they were unable to provide details on medical interventions used in the previous 6-months.

Many reported they had not attended a General Practitioner (GP) for the management of their CFS in the previous 6-months. The reason provided was that they were not able to find a GP who could help them or who understood their illness.

During one of the focus group discussions, a participant asked for clarification on 'care planning' in the General Practitioner context. This opened a constructive discussion in which participants described how they planned their GP visits. It was agreed by most that to maintain an ongoing General Practice relationship '*it was important to talk only about one or two medical matters, as GPs cannot cope with the multiple effects / symptoms of CFS in one visit*'.

These health consumers were not sure whether they would be prepared to raise the question of 'collaborative care planning' with their doctors because this would require them to discuss their broader life needs and expectations. It would also mean that they would need to tell the GP of the other services / providers they planned to attend in the next 6-months. Some expressed the fear that this might put at risk their current relationship with their General Practitioner.

This highlights an important matter for policy and program service planners because it indicates how far sufferers of a complex chronic illness such as CFS feel inhibited from requesting assistance from those best placed to help them. This does not mean that patients did not recognise the importance of the ongoing doctor patient relationship, but

of **their perceived need to adapt their behaviour, expectations and communications to maintain General Practitioner relationships.**

Community services

As stated **most respondents did not have access to community services.** This not only included home and community care' types services but also hospital, General Practitioner and allied health care to support them in times of health crises or relapses. One reported being turned away from a hospital Accident and Emergency Department on the basis that they had a chronic medical condition. Most respondents wanted to extend the discussion and share their many adverse experiences and talk about the stigma associated with the name 'Chronic Fatigue Syndrome'.

They reported that they were not eligible and believed services did not understand about CFS and its associated physical and cognitive limitations and multiple chemical sensitivity reactions. Having been turned away in the past meant that respondents in this study did not keep in touch with local community service agencies and they did not know of new services such as chronic disease management educational programs and other potentially helpful community activities. Most services used were in the private sector, fee-for-service and were not long-term because the cost was prohibitive.

Some individual sufferers accessed services by other means e.g. those on Disability Pensions had access to "Home Assist" in the Onkaparinga Council area, while others accessed services through 'high disability scores' e.g. disability associated with arthritis.

As stated, contact with community services revealed that while people with Chronic Fatigue Syndrome are not seen as a client group, or fit into most agencies' service priorities or met currently defined service access criteria, **staff expressed support for the work to improve information about CFS sufferers in their area.** These agencies agreed with the goals of this project because they were unclear as to the numbers of CFS clients in their service area, their levels of disability and the types of services accessed / not accessed by CFS consumers. **Services did not record 'requests for services' where clients were not accepted or eligible.**

For the above reasons, agency staff provided assistance and in turn requested copies of the findings. They advised however, that access to their services was dependent upon

applicants fitting into the approved predetermined categories under the Home and Community Care Program. (HACC) type funding priorities and agreements.

The service usage / needs information gathered from participants is thus identified as 'baseline' because there is no alternative systematic data source, and 'for further development.' as future service evaluations and research becomes available.

Community Development / Empowerment / Provider Consumer Relationship

While the primary purpose of this study was to gather information, it is a work-in-progress because those participating frequently advised that they would like further time to think about these new approaches to managing their CFS. Focus Group participants describe how this gave them hope and a new perspective on using services to help them in their daily lives.

'Community development' and thus education / empowerment inevitably came to be a major and integral part of the focus group research process / experience.

As described above to achieve the desired outcomes of this study it was necessary to spend time providing explanations and promoting the wider Chronic Disease Self-Management, Enhanced Primary Care, Sharing Care Program initiatives and how these can benefit people with CFS. It was hoped that spending time on the explanation would begin to address the lost confidence in medical care and formal support services.

The process of documenting and highlighting the nature and extent of CFS patients' needs, not only informed the latter, but locally began the process of addressing South Australian and other CFS patients' previous long term lack of confidence in medical care and their failure to benefit from access to formal support services already available to most other people in Australian with comparable levels of disability.

A consequence of their being 'invisible' to community service providers is that CFS sufferers are remarkably unaware of the purpose, existence and potential value of using these services to prevent further disability and enhance their well-being. **Education is a crucial factor in 'self-management' and moving patient / client care from a 'medical / acute care' model to the 'chronic disease self-management' and/or 'collaborative multidisciplinary care management' models of the Enhanced**

Primary Care / Chronic Disease Self-management Initiatives. In reality these models require the knowledge and acceptance of the concepts of 'wellness', 'collaborative care', 'prevention', management and self-determination.

Consistent with the community development / empowerment approach, a considerable part of the time devoted to the focus group and phone interview activities was taken to acquaint sufferers with the 'collaborative care planning' context of the questions and the new approaches to care, and their potential short and long-term value for people with long term medical conditions such as CFS.

Whilst most responses were in practice obtained via phone interview, the 'focus group experience' yielded uniquely valuable data and provided a 'context' into many other aspects of sufferers' current situations, which vary considerably according to each persons' illness experience, experience of prior medical interventions, age and geographical location.

For this reason the focus groups proved to be strongly motivating for sufferers who participated in them and also for the researchers because they provided insight into implementing theory and policy into the daily lives of sufferers of chronic illness in South Australian community settings. People with CFS who heard about the groups from others wanted to participate in one when they were able. Whilst the study timeframe did not allow repeat focus groups, most participants advised that they would have attended a second one after they had time to process the new information.

People's expressed needs were affected by their illness experiences and expectations, their life stage as well as their actual Chronic Fatigue Syndrome symptom patterns and associated disabilities.

For all these reasons, reaching out to CFS sufferers proved to be, and will continue to be, a time consuming activity that requires understanding of the importance of community development consumer research frameworks. It requires the re-orientation of services from illness /sickness models of care to the already well tested wellness, prevention and health promotion models of care i.e. *What is possible to maintain an acceptable quality of life?*

8. RESULTS: SECTION THREE

Service Planning Matters and Current Service Lists

This section presents results relating to the aim of providing information up-to-date information on the current and potential use of services by people with the Chronic Fatigue Syndrome (CFS) group of disorders.

We here list the priority service issues and recurring themes arising from the structured interviews conducted between June and December 2002.

Remarkably respondents (109) did not have unrealistic expectations about services. The **priorities for all participants were reliable information and equitable community access and acceptance** including the addressing of multiple chemical sensitivity, environmental issues that affected their day to day survival, living in the community and their relationships with providers, family and friends.

As described above, despite describing unacceptable levels of disability and deteriorating health many participants in this study had given up trying to get help through medical, health and community services.

‘Sufferers’ dominant motivation was their persistent commitment to remaining ‘normal’ members of the community i.e. participating in activities such as shopping, eating out and being able to live with a high degree of independence of others as well as being accepted by family and friends.

Several participants had moved to more suitable housing after having identified problems such as size of accommodation and its proximity to shops, services and transport and chemical sensitivities. Many of the Victor Harbor participants had moved there solely or mainly in an attempt to move to a location where the environment was presumed to be less affected by chemical contamination of a kind likely to cause further decline in their health and well being.

INFORMATION - important

Standardised Information Access: Available, Reliable and Up-to-date

Respondents placed great importance on information and that this must be improved, available and frequently updated and that the delays or gaps between research and treatment information accessed on the Internet and the daily care available to them was not acceptable.

People believed much of the information being circulated was inaccurate and that this disadvantaged them in medical, other health and community service care and in turn led to unnecessary loss of income and discrimination in 'CentreLink' (income support) assessments and 'Work Cover' claims. Many wanted to provide details of how this had caused problems with personal treatment choices that lead to needless suffering.

Respondents believed the problems with misinformation directly led to family / relationship breakdowns and unnecessary loss of work / income. They described the generally fluctuating character of their many and often unexplainable symptom patterns as leading to misunderstandings and being interpreted inappropriately.

'I am an intelligent person and I think I am going crazy, so I can understand that my friends and service providers really think I am, but that is no excuse for not providing us with care and treating us like lepers.'

Informants said that information needs to be standardised, but also frequently updated and circulated immediately to doctors and other relevant service providers.

For consumers, they recommended that there is a need to disseminate up-to-date information on what is already available in the community to support sufferers, families and carers to make good choices. This should **be easily accessed so people can obtain it in the early stages of their illness.** Such information should

1. facilitate greater choice of the different interventions and types of care available also
2. instruct families and friends of sufferers about Chronic Fatigue Syndromes and of their often unique symptom-profiles.

Suggestions for the information required

- standardised
- user friendly
- current and relevant
- clear about good and bad outcomes
- easily accessible in the local community, e.g. community notice boards
- clearly understandable by people with CFS, many of whom have reading or comprehension difficulties.

Purposes of the information identified

- to help family members and others to understand CFS sufferers' problems
- to make known possible side effects
- to list treatment choices clearly and their pros and cons
- to provide information on the best and latest treatments to medical providers (the gap or length of time between research findings and their implementation in General Practice was not acceptable, sufferers believed this was affecting their poor health outcomes).

Information on medical and other health providers available in South Australia

- service lists to include medical, allied health and integrated care providers and their service types etc. This to include naturopaths, chiropractors etc.
- a registrar of doctors who understand and are sympathetic towards people with CFS, and that for each doctor includes data on the doctors' approaches to
 - assessments and management relating to CFS
 - treatment used
 - their approach / philosophy on long term medical conditions
 - clinic waiting list times
 - the availability of home visits.

Information on services, management and treatments available in South Australia

- treatments and helpful interventions lists
- information on side effects of medication and other treatments. Sufferers described treatments that made them worse before they got better while others described ones that made them worse and left them with increased levels of disability.
- service access accommodations e.g. disability, cognitive problems, transport, chemical sensitivities
- information on vaccinations related to CFS-immune system problems
- reliable / validated information on research and overseas treatments available to them via Internet and CFS Society Journal.

Information about access to specialists

- respondents did not identify specialists in South Australia who they had found could help them with their CFS.

What do different specialists do?

What, if anything can each kind of specialist contribute to the care for CFS sufferers?

You can wait months for a specialist's appointment only to be told that there is nothing wrong with you or be dismissed with no new information

...

... and you don't even get a chance to ask questions

Environmental / Service planning access problems identified

- waiting rooms separate from those used by other patients – to avoid unnecessary contact with 'infection' or 'chemical problems'
- chemical-free doctors' surgeries and hospitals
- flexible times; services available at differing times of the day
- shorter waiting times
- facilities for lying down while waiting
- home visits: by G P and other professionals

- access to specialists who collaborate with GPs and other providers and understand the complex nature of multi-system disorders.
- appropriate hospital access - advocacy, liaison, peer support
- services in local area and /or transport to medical appointments
- costs of even basic management intervention and services e.g. Subsidised care and medications

Central Site to report / record service access problems

- central site for reporting / recording service problems.

Access to prevention and / or early intervention a concern

Respondents frequently requested access to early intervention including rehabilitation, other therapy and prevention approaches. They believed information to help them understand the changes and to limit the illness process and disabilities and the associated life losses (income loss, dropping out of study, social isolation etc) was a crucial factor in the management of their chronic condition.

Many respondents directly linked their current levels of disabilities to the lack of appropriate care, information and services to help them. They believed that better care in the early stages of the illness would have limited their level of disability and even prevented them losing their work / income.

Suggestions about General Practitioners and other providers

should, ideally

- understand the different types or variations / groups or spectrum of Chronic Fatigue Syndromes and that people had individualised needs.
- avoid rapid 'pigeon holing' diagnoses which precludes further investigations
- be willing to listen and non judgmental
- doctors: take time to listen to real needs and patients' illness experience
- importance of validation/acknowledging of illness symptoms in syndrome disorders. (This includes changes in symptom levels/patterns in order to reduce patient fears and stress during treatments)
- early warnings on post infection fatigue

- in the early stages of the illness there is a need to alert patients to minimising of stresses and for grief/loss counselling
- early access to pain management
- recognition of cognitive problems related to remembering treatment regimes, filling in forms, reading, and comprehension
- patients cognitive problems need to be recognised in care
 - receiving and providing information
 - memory / concentration issues
 - speech / word use can be affected
 - fluctuating visual sensitivities.
- individual providers need to explain long term effects of treatments and research they are prescribing
 - *'Cortisone may improve pain levels but at cost of general health and long-term severity of the illness'* (they believed doctors need to know this)
- individual providers should be accountable and willing to share their treatment protocols
- some providers including General Practitioners charged high prices for CFS treatments (examples provided included \$300-500.00 per sessions, \$10.000 for a treatment program, \$20.000 for an inpatient regime). These treatments did not have positive outcomes.

Access to Tests and Assessments

Respondents raised problems with pathology and other diagnostic tests not available to them in South Australia, this included particular types of tests as well as the costs being prohibitive. They requested that testing should be linked to patient's history and symptom patterns and changes and not 'blanket' related to the term 'CFS'.

People with Multiple Chemical Sensitivity identified how they were excluded from some relevant tests because of the dyes and markers that caused them reactions.

List of issues relating to diagnostic and treatment tests:

- pathology testing both for diagnosis and treatment monitoring should be available under Medicare
- results to be interpreted from the patients' illness history.
- tests for long-term and intracellular infections related to current knowledge of chronic illnesses
- biochemical and metabolic blood and urine tests e.g. Newcastle type to support nutritional supplement theories and diet modification recommendations
- tests for toxins and allergens etc
'some providers make a lot of money out of these while others dismiss them and will not even discuss them'
- SPECT SCAN, MRI.
- blood pressure testing related to orthostatic hypotension / tolerances, low blood pressure research findings.

'some doctors don't even know that there are different types of testing ... what's more they are not willing to even make a phone call to check in case there may be some information they are not up-to-date ...'

Six Priority Management or Intervention Areas Identified

Focus Group Participants detailed six (6) priority intervention areas that they believed were important in General Practice care for people with long term CFS.

They believed that doctors need to be educated on how different types / groups of CFS patients respond and that individual patients may have diverse responses and what works for one does not work for everyone.

1. Sleep management

- Quality of sleep, affects of insomnia important
- Sleeping pills vs. other management strategies
- Comfortable bed e.g. egg shell mattress for pain
- Resting / sleep management, plan
- Sleep, Naps.

2. Pain management

- Important but how – more investigations required
- Waiting lists for pain clinics too long (symptoms worsen while waiting)
- Pain management clinics do not recognise CFS and Fibromyalgia types pain
- Balance between medication and other strategies.

3. Depression management

- Understanding that *'you get depressed when you are ill and can not get help and that you are not just depressed'*
- Medications – appropriate for different types of CFS and individual patient differences
- Grief counselling.

4. Movement, exercises and muscle and bone maintenance

- Access to physiotherapy, massage
- Appropriate and individualised exercise regimes
- Deep massage has negative effects, providers need to know the types.

5. Cognitive Problems

- Acknowledgement
- Accommodations
- Skills programs
- Access to psychologists and occupation therapists (Medicare / cost)

6. Diet Management

- Providers, including doctors, naturopaths, other integrated health providers. Newspapers and the CFS Society journal frequently promote diet as an essential part of CFS treatment, but the information available is conflicting.
- Only in one focus group, Victor Harbor, did participants have access to a dietician.
- Participants' approaches to diet and the foods eaten and / or not eaten varied widely.
- Most participants described personal observations of how various foods eaten affected their symptom levels.

- Problems raised also related to their inability to be able to prepare meals during relapses.
- Prepared meals for special diets were not usually available
- Costs can be prohibitive to healthy eating
- Delivered or pre-prepared meals were used 'Meals-on Wheels', 'Light and Easy', 'Nushape'.

Diet issues identified by participants varied but included

- Some foods improve / worsen health and well being
- Non-processed food / chemical free
- Avoiding allergies to foods, fats, sugar, etc
- Dairy free?
- Juice: what helps the individual e.g. carrot, celery, beetroot, apple - freshly prepared
- One person identified the 'Liver cleansing diet' others stated it made them worse.

Other current Management issues / themes for CFS sufferers

More and more consistent information on:

- **Management of Chronic Infections** - further information e.g. Rickettsia, viral and other infections in long-term medical conditions etc.
- **Management of symptoms** (in context of complex disorders) e.g.
 - Thyroid related abnormalities and treatments found in CFS patients.
- **Blood pressure related problems**
 - balance, standing problems, vertigo i.e. orthostatic hypotension management.
- **Management of Multiple Chemical Sensitivities and / or intolerances**
 - Individual / environmental / building / workplace related
 - Community, local Government aspects of management / aerial spraying
 - Problems related to diagnostic tests that make them worse (dyes, radioactivity)
 - Hospital environmental & staff attitudes.
- **Management of medication sensitivities**
 - Doses: people believed they could not tolerate normal recommended doses
 - Problems experienced with medications need to be centrally recorded so others (doctors & sufferers) can be made aware
 - Instructions need to be easy to follow, for CFS sufferers who cannot always read / understand package inserts because of visual, memory and cognitive problems.
- **Miscellaneous Treatment Issues**
 - Problems related to medications and other treatments provided by doctors who did not understand that there were different types of CFS were frequently raised.
 - Dilemmas over conflicting information arising from different providers' opinions were cited by respondents

- Several respondents named treatments that had lead to increasing their level of disability.

Support in the community during treatments / side effects essential.

Several people identified the importance of information and support during treatments. Respondents described how treatment interventions directly influence symptoms experienced and may even change the symptom patterns and levels of pain. This can be unsettling or even cause panic. As one person described it:

'I could not move' ... 'My pain levels increased and the focus areas of the pain changed; I could not breathe'. 'It was only when I talked to another sufferer that I found these changes might be temporary and part of the readjustment process'.

More efficiency in making treatments available:

- Costs, brand variation and mark-ups
- Physical access
- Monitoring and follow up

Treatments identified by several participants

- Serine
- Serotonin replacement therapy
- Hormone replacements – oestrogen
- Folic acid and Vitamin B12 injections – B6 injections
- L-carnitine
- Rickettsia treatment
- Fish oil (omega 3), Efamol (brand)
- Magnesium and 'Muscle Ease'

Treatments identified by only one participant

- Massage
- Respite – getting away from their own home to the seaside town ‘away from chemicals’
- Bowen Therapy
- Co-enzyme Q10
- Zinc
- Vitamin C
- Acupuncture
- Relaxation, meditation
- General vitamins
- DHEA, health pharmacy
- Gingko-biloba
- Aromatherapy
- Ayurvedic therapies including massage
- Biocom, electromagnetic treatment (to remove toxins).

Management Issues important to Chronic Disease Self-Management Frameworks (collaborative holistic care, quality of life, adapting to the illness)

Most participants in this study were 'long-term' sufferers who had modified their lifestyle in order to live with CFS. They did not always identify such lifestyle modifications as 'skills development' or 'resourcefulness' in chronic illness management. While people argued that they had a long-term medical condition and had in fact adjusted their lives many still had expectations of a miracle type cure.

Self-management was not viewed as positive

Self-management was not viewed as 'positive living' with the illness limitations but as negative or striving to be 'normal'.

People did not always recognise that they had developed new skills relevant to self-management, or that these skills might usefully be shared with others in the focus group, or in a positive way to help other CFS sufferers and their families.

Community / family acceptance important to quality of life

Participants did not perceive themselves as accepted in their communities or even within their own families. They described themselves as **'non-accepted' and 'misunderstood', living as they do in a community where there are no accommodations for people with complex chronic conditions including hypersensitivity to chemicals.**

For this reason they again gave **precedence to their request for better, clearer information to help family members understand their problems** and for initiatives to promote community understanding and awareness that 'CFS' is far more complex, debilitating and disabling than merely 'being tired'.

In this same context long-term sufferers repeated the importance of 'early diagnosis' 'early intervention', because they believed many of their problems had been increased because of 'mismanagement' and 'misinformation' in the early stages of their illness which if addressed

'will prevent other people from suffering and losing their family or their job like I did'.

'Housing or accommodation' - an issue for people with CFS

Housing emerged as a priority theme

- affordability: rent assistance / housing trust / housing co-operatives
- appropriate housing: chemical free indoor environments
- transport problems: close to facilities / shops / medical care
- housing modifications – low stamina, poor balance etc access to occupation therapist /subsidised tradesmen
- housing designs that allow for low energy costs etc
- availability of 'home care': doctors, physiotherapy and community service providers. Respondents identified that the provision of these varies across local government areas so people may need to relocate to access services
- may need to be physically separated from neighbours who use particular household chemicals
- not in industrial or agricultural areas generating fumes or chemical sprays, this included sensitivity to 'pine forest toxins' and grapevine areas
- warnings from council about activities e.g. spraying, mowing and fuels etc. Some councils keep lists of 'chemical sensitive' and 'housebound' residents' and when requested will advise locals or limit spraying, or in the case of a summer fire warning they will send an ambulance to evacuate the person.

'Social Isolation' - an issue for people with CFS

- respondents told of how your friends drop off when you are always sick or 'cannot do the normal things with them'
- access / links to other people with CFS: 'positive attitude' support groups / 'groups that help with living' not 'unusable research that gives you false hope'
- people who can help understand / validation of illness experiences
- empathetic attitude towards life / illness
- need friendly visits
- disabled parking permits help getting out / related to limited walking problems.

'Maintaining usual lifestyle' - an issue for people with CFS

- lifestyle – general change and adaptation = management
- balancing staying at home to minimise symptoms vs. avoiding social isolation
- problem solving skills
- sleep, naps
- counselling,
- grief and loss
- conflict resolution skills
- mediation / advocacy skills
- loss of income, problems with sickness and disability income support claims.

'Crucial aspects of Self-Management' identified by respondents

- Doctors / communication skills / time limits too restricting for patients with complex chronic illnesses
- Cost of treatments, information on sources, prices, (need for subsidies to enable people to continue with helpful treatments)
- Flexible services times and programs by people who understand CFS problems
- Skills required to self manage e.g. help from carers / communication with doctors?
- Monitoring energy levels in regards to how much energy is required for particular activities, 'contracting self out'
- Staying at home to reduce symptoms / stress vs. avoiding social isolation
- Resting / sleep management, daily (and weekly) 'energy budgeting plan'
- Managing time / 'deadlines are deadly'
- Reduction of stress
- Pacing self, not 'overdoing it' to meet deadlines or to keep up with others.
- Determining which foods improve / worsen symptoms, moods, well-being, short and long-term effects
- Financial management
- Subsidised natural therapies
- Varying and individual variations in tolerances to different chemicals
- List of chemical-free products and better labelling.

'Movement and exercise'

- Walks, graded and realistic opportunities for improvement (or to maintain current movement level)
- Access to physiotherapist, occupational therapists and personal trainers.
- Swimming, chlorine-free pools
- Hydrotherapy.

'Information access' - availability / reliability

- Relevant information via e.g. community notice boards / 'word of mouth' / phone-links
- Information and service availability gaps between the research treatments available to people via Internet and 'Medline', and distributed in Chronic Fatigue Syndrome Journals and not available in Australia.
- Respondents had travelled interstate and knew others who had travelled to USA and South Africa to obtain treatments that they had read about on the Internet.
- Up-to-date clinical type information that covers the complex nature and range of clinical patient presentations of CFS for General Practitioners, specialists and hospital Accident and Emergency Departments
- Information needs to be user friendly and recognise CFS cognitive and comprehension problems.

'Service access to support self-management' - / maximise independence.

- provider home visits
- services available at differing times of the day
- transport - close to facilities
- disabled parking and access.

Access to Income Support

- CentreLink or welfare support to recognise CFS clients?
 - The importance of maintaining work / income where possible
 - Part time work
- Disability assessments / assessors who understand CFS

- Need for help to understand system and for advocacy
- CentreLink problems / recognition increase problems with superannuation and other work benefits
- Physical ability to get to centres to apply and meet appointments and deadlines
- Filling in forms, because of cognitive problems, brain fog, memory concentration issues
- Help or accommodations needed relating to illness status and the fluctuating unpredictable nature of CFS symptom expression.

Domiciliary and other home based services

- to help adjust to changes because of the illness
- to maintain an independent existence
- to enable rehabilitation
- service access during relapses, health crises or when not coping
- essential services include
 - meals / eating
 - shopping
 - washing of clothes
 - essential cleaning
 - home maintenance
 - to help meet Housing Trust demands of residents.

Meals

- access to prepared foods (even Meals on Wheels) particularly during relapses
acknowledgement of food sensitivities in diet supplied from outside home
- other special dietary requirements.

Miscellaneous support needs identified

- Support for mothers and families e.g. childcare, and during crises and relapses
- Support groups in local communities close to residence where possible.

Environmental issues relating to multiple chemical sensitivities / reactions

As stated **the main priorities for people with CFS were environmental issues related to living in the community and having access to essential community facilities.**

Respondents reported experiences of encounters with 'chemicals', even 'natural' substances such as 'pollens', or even breathing air-conditioned air could exacerbate their ill health.

External Environment

- Climate factors: seasonal temperatures and winds may exacerbate symptoms
- Allergies: pollens, toxins (domestic, industrial, hydrocarbons, perfumes)
- Clean environment: environmentally friendly, chemical free, quiet/tranquil
- Notification of weed spraying, other associated spraying of chemicals e.g. termites, fruitfly
- Road works, service repairs / gas repairs / fumes e.g. paint, fuel / Port Stanvac oil refinery
- Country living? It is easier to control exposures away from cars factories etc but need to know about aerial spraying.
- Dry cleaning – toxicity
- Community database – some Councils have information on the chemical sprays they use and record where they are using them.

Building Environment

- Access to services via waiting rooms isolated from 'infected' or 'toxic' patients
- Access to chemical-free cleaning and other services
- Low toxicity chemical building materials (avoid formaldehyde, solvents etc)
- Shopping centre air-conditioning may circulate toxic substances e.g. perfumes insecticide, solvents, hairsprays, detergents.

Work Environment

Access to work and income support is affected by differing interpretations of chemical exposure acceptance issues

- Exposure to chemicals / toxins
- Part-time / adjustment of hours etc
- Rehabilitation, work re-entry
- Disability assessments / assessors must understand CFS and other complex chronic disorders.

Some respondents believed that if these were managed more efficiently there would have been a reduced burden on them as individuals and on the health and welfare system.

Schooling and University Environment

- Accurate information relating to early and appropriate intervention
- Accurate information relating to cognitive problems & other illness limitations
- Information on how to avoid / counter / limit long-term effects and work problems
- Information for counsellors on the need for cognitive / learning / educational / accommodations
- Provisions by educational institutions of breaks, e.g. during exams or allowance for extended or staggered assessments.

Families and Carers

- Written information to help with understanding of CFS sufferers
- Family and carer training
- Carer respite
- Information, explanation sessions.

9. CONCLUSIONS

The goal of this focus group study was to reach and gather information from people with CFS in a pilot geographical area, the Southern and Hills Districts of Adelaide South Australia. The information gathered needed to be representative of the real needs of CFS consumers in that community and consistent with community service planning and funding priorities.

The type of information required was new information to supplement individual patient care and to support community service, policy and program planning and funding.

The results of this study are from information gathered from 109 people living in the local area during the 6 month period June 2002 December 2002.

The objectives were to gather current and representative data from people with CFS that is useful for providers and service planners appropriate for their participation in Health and Community Service improvements (EPC and Chronic Disease Self-Management Initiatives).

As stated the study found that sufferers' loss of confidence in services affected the information people provided. The people with CFS reach were mostly (80%) house bound and had not attended a General Practitioner for their care in the previous six months. They were not participating in self-management activities, did not have access to community services and were not aware of the services in the community that might help them. Most participants were not able to identify a General Practitioner or other medical provider whom they felt understood the complex nature of their medical condition.

This loss of confidence and perceived lack of help had lead them to restrict their daily activities and to a feeling of being ostracised. At the time of the study community access and acceptance issues (environmental and social) were their priorities because these matters affect their ability to obtain food and medicines and to mix with people in the community, in their local shopping centres and to interact with their families and friends.

They were not used to planning ahead and/or working with a case manager to use a range of health and community services. This did not mean that they were not

interested in multidisciplinary care planning to improve their quality of life, because the focus groups and phone interviews appeared to spark people's interest in following through the questions discussed, and they are continuing to provide information on the issue.

Respondents placed great importance on information. They felt their situation would be improved if up-to-date and accurate information was available. This needed to include the different approaches to the management of CFS, reducing time gaps between research reports and actual providers care, and include CFS appropriate CentreLink assessments.

People felt that if the appropriate information had been available to them in the early stages of their illness, it would have limited the severity of their illness and disability and even prevented their loss of work and income and their subsequent long term dependence on the welfare system.

If this information on the complex nature of CFS was available to service providers perhaps they would be less judgmental and able to accommodate CFS sufferers with services to help them. What happens now is a breakdown of consumer provider relationships that leaves the sufferers further misunderstood and deprived of essential services that would make everyday life more comfortable.

In relation to medical care, people identified the need to be individuals and for their tests and subsequent care to be interpreted against their personal illness, work and environmental history rather than being generalised. The study found six priority management or intervention areas, which are of importance to CFS sufferers these are detailed on p 43- 45.

As stated the service lists in Results Section 3 are presented as baseline data for further development based on future research, evaluations including outcome measures of people with CFS participating in EPC care planning activities.

The unexpected high level of disability affected the number of participants who attended the focus groups. In this study phone interviews based on the same structured question of the focus groups gathered information from more people. This was because people stated that they were not well enough to attend a group meeting.

The combination of focus groups and phone interviews enabled data collection from more CFS sufferers including people from the severe end of the illness who are often excluded from other studies.

The findings of this study were that the focus groups were an effective tool to gather representative data from people with CFS and also to educate / inform them enabling group interactions and problem solving. However for CFS sufferers, participation in focus groups is influenced by the weather and season, time of day, environmentally friendly chemical free buildings and available transport.

The final data gathered not only achieved the study outcomes to collect new information to support service improvements and to inform policy developments, but it also provides the context and insight into the daily lives of people with CFS. People stated they were more willing to share experiences in face to face situations rather than with a printed questionnaire.

Extending this cost-effective approach to data collection to other areas of Australia would expedite a reasonable process of gathering representative information on services for people with CFS. This would make available the baseline data important for health planners to include Australians with Chronic Fatigue Syndrome (the Australian CFS Guidelines S28, estimated the prevalence 0.3-1.3% in primary care settings) in the next stages of the chronic illness program and service reform initiatives.

Until progress can be made across a broad front to expedite such a process and to implement a cost-effective implementation framework that facilitates the provision of basic services to people with Chronic Fatigue Syndrome there will continue to be unnecessary suffering.

This process and framework would ultimately overcome the current situation of the denial of access to services, including the availability of useful information, that leads to worsening of the 'illness experience', increased disability and unnecessary long-term dependence on the health and welfare system. **It is a reasonable hypothesis that applying the core principles of Primary Health Care and Chronic Disease Self-Management programs i.e. 'social inclusion' 'community participation' 'self-management' and 'equitable access to timely and appropriate services' will limit**

the impact / burden of Chronic Fatigue Syndrome on individuals, their families and the Australian community.

To Summarise

This pilot-study conducted in the Southern and Hills districts of Adelaide has revealed: -

1. these clients, people with Chronic Fatigue Syndromes (CFS) and associated disabilities, are not participating in outcome focussed General Practice care planning / coordinated care, or chronic disease management approaches to health and community service delivery
2. that participants in this study were not aware of the services available in the community that could help them to improve their health status or quality of life
3. that participants were not able to access or were excluded because they did not meet the assessment criteria for health, home and community care (HACC) and disability support services available for such clients, particularly when compared with those currently available to other Australians with comparable levels of disability and complex care needs
4. a worrying loss of confidence in General Practice, and other health and community services
5. inconsistent or the lack of up-to-date or information circulating in the community is misleading both consumers and providers and thus influences short and long-term health outcomes.
6. participants had realistic expectations, much of the serious shortfall in service provision revealed by our study being remediable if people with CFS were to gain equitable access to Federal, State and Local Government funding and services
7. an urgent need for provider and consumer education on how '*outcome-focussed service delivery*' and '*Chronic Disease Self Management*' frameworks (Department of Health and Ageing, 2000) can address many of the generic care needs and service problems of Australians with long term medical conditions,

including poorly understood disorders such as the Chronic Fatigue Syndrome group.

The study's conclusions include a recommendation that extending the Federal Department of Health and Ageing Initiatives of Enhanced Primary Care, Chronic Disease Self-Management programs designated for '*all Australians with complex chronic conditions*' (EPC, 2000) to people with poorly understood complex chronic illnesses such as the Chronic Fatigue Syndrome group will:

1. improve their health outcomes and reduce their associated levels of disability
2. facilitate early intervention and preventative care and reduce loss of confidence in health services
3. prevent loss of income / work and long term dependence on the health and welfare system
4. reduce the burden of CFS on individuals, families and the Australian community
5. reduce the currently unacceptable delays between research and clinical practice and facilitate the provision of current best practice community care not yet available to these clients (Couper MJA, 2001; Community Consultation Submissions to Australian CFS Clinical Guidelines, 1996 & 2002)
6. provide a cost-effective equitable solution to the ethical dilemmas and service and information quandaries associated with poorly understood chronic disorders known as Chronic Fatigue Syndromes (Myalgic Encephalomyelitis, ME/CFS) in the Australian community
7. facilitate an ongoing systematic data collection process based on patient health outcomes and appropriate health and community service interventions for this client group.

Improving services based on the principles of equitable access would be realistic cost-effective path to limit the poor health outcomes, unnecessary loss of work / income and increased levels of disability. As CFS is mostly a non-progressive and non-degenerative disorder this would reduce much of the need for long-term health and community care

services and facilitate inclusion, early intervention, prevention and rehabilitation in the early stages of the CFS illnesses processes.

APPENDICES

Appendix 1: Consumer Group Information Chronic Fatigue Syndrome, CFS, is a long-term medical condition

Appendix 2: ME/CFS Primary Care Best Practice Research and Evaluation Project

Appendix 3: Structured interview format

Appendix 4: Model Guidelines for the Management of Chronic Conditions, Western Australian Royal College of General Practitioners June 2002

Appendix 5: Focus Group Kit. contents

**Appendix 1: Consumer Group Information Chronic Fatigue Syndrome,
CFS, is a long-term medical condition**

Appendix 2: ME/CFS Primary Care Best Practice Research and Evaluation Project

Research Hypothesis (1999-2005):

Improved access to timely and appropriate care and reliable information will lead to improved health outcomes for people with Complex Chronic Disorders, including the FMS/ME/CFS group of illnesses, and limit the impact of their associated physical and social disabilities.

Our Mission

To improve the health outcomes of all people affected by the Complex Chronic Syndrome Disorders, particularly the FMS/ME/CFS group of overlapping disorders.

Overview:

This solution-focused research project facilitates collaboration and communication between people with Chronic Syndrome disorders, their providers and support groups. This project is a forum working to support communication, service improvements and continually circulate user-friendly information among patients and providers.

Aim of the project:

To reduce the burden of Complex Chronic Disorders (FMS/ME/CFS) and other overlapping long-term medical conditions on individuals, their families and the Australian community.

This project works to improve the access to a range of timely and appropriate holistic multidisciplinary services to limit the impact of the illnesses (Federal Enhanced Primary Care /Sharing Care Initiatives, 1999).

More specifically, it aims to:

1. Facilitate consumer provider partnerships to identify service gaps and to work together to better meet the needs and lived experience of FMS/ME/CFS consumers.
2. Support General Practice outcome-focused, structured multidisciplinary care planning.
3. Empower and facilitate FMS/ME/CFS consumers.
4. Provide a focal point for information sharing around improving health management and the availability of care interventions and community services.
5. Facilitate immediate access / crisis care to prevent unnecessary suffering.
6. Support smaller service agencies to demonstrate how their work contributes to improving outcomes.
7. Foster participatory evaluations for improved outcomes consistent with service. evaluations from the wider Australian health system.
8. As arising, investigate and circulate risk management issues for harm minimisation and service improvement in a non threatening environment.

Current Research Activities:

The project is currently in the process of:

- Gathering baseline information on current services and management strategies used by Australians with FMS/ME/CFS, their families and carers
- Identifying the range of sufferers / groups within the community
- Providing information to community information centres (national / state)
- Identifying, facilitating and evaluating service and education modules
- Working towards solutions of better management for chronic illnesses
- Identifying individuals, groups, organisations, government and service agencies with similar goals and values
- Strengthening communication networks.

Appendix 3: Structured interview format

CARE PLANS FOR PEOPLE WITH ME/CFS/FM/MCS

Care is tailored for each persons' needs and include measures to help you and your doctor monitor your care.

What things would you include for people like you with MECFS/FM?

◆ **Things That Affect My Health (in the next 6-months)**

Impact of illness (mobility, feeling isolated, energy levels etc)
Symptoms to monitor (e.g. fatigue, pain,)
Lifestyle (financial, housing, shopping, daily activities)
Self Management (other providers, services, natural/alternate)

◆ **My Goals (Long term/Short term i.e. 6-months)**

Impact→ To increase activities e.g. gardening, etc.
Symptoms→ Reduced by?
Lifestyle→ What helps?
Self-Management→ Improve confidence, skills, other.

◆ **What will I Do To Improve My Health this 6-months?**

(Impact/Symptoms/Lifestyle/Self-Management)

Get involved in activities, Diet, Movement, flexibility, walking
GP/Other Providers/Medication
Family support/Carers/Services
Planning, pacing, monitoring

◆ **How Can I Do This/ Who Can Help Me?**

Which services help me accomplish my goals?
Which services aid these needs?

SUGGESTIONS (Please write below)

**Appendix 4: Model Guidelines for the Management of Chronic Conditions,
Western Australian Royal College of General Practitioners June 2002**

Appendix 5: Focus Group Kit. Contents

Focus Group Kit / Tools: Leader's Pack – contents

1. Introduction to ME/CFS (South Australian Society's handouts (use your local society handouts))
2. RACGP Sharing Health Care Sample Care Plan
3. Tool 6: Conducting a Focus Group (***) Mental Health Consumer Handbook)
4. Standard letter to Health Providers and Community Centres re Focus Groups to held in local area
5. Focus Group advertisement/notice for community notice boards
6. Focus Group leader's introduction and checklist
7. Focus Group Leaders records sheet
8. Introduction to National Taskforce Focus Groups (version 1) (Pre Focus Group mail out)
9. Introduction to National Taskforce Focus Groups (version 2) (Pre Focus Group mail out)
10. Introduction to Focus Group 1.1 (handout at first Focus Group)
11. Introduction to Focus Group 1.1 (updated post Focus Group)
12. Focus Group prompt sheet; to use during session
13. Focus Group prompt sheet; to take (and return)
14. Care Plans for people with ME/CFS/FM consumer pilot Draft 1 November 2002
15. Care Plan for people with ME/CFS/FM (4 pages)
16. National Taskforce thank you.