

A.W. and K.D.

1 July 2008

Email: [fchy.reps@aph.gov.au](mailto:fchy.reps@aph.gov.au)

Secretary,  
Standing Committee on Family, Community, Housing and Youth,  
PO Box 6021,  
House of Representatives,  
Parliament House,  
CANBERRA ACT 2600

Dear Secretary,

**STANDING COMMITTEE'S INQUIRY INTO BETTER SUPPORT FOR CARERS**

We would like to provide input to the House of Representatives Standing Committee of Inquiry into "Better Support for Carers".

From our point of view, based on some 15 years in the carer role, better support for carers will be determined for the most part by the quality, range and level of primary care and support available to those in need of care. If primary care can be co-ordinated to provide quality outcomes, the need for support of the carers will be substantially reduced.

As things stand, some of the more vulnerable of the community in need of care tend not to be appropriately identified and are without appropriate access to the full range of support needed to ensure their safety and wellbeing, both in the short to longer term.

Often carers witness situations where the person in need of care is failed by the system intended to co-ordinate or deliver the essential support. This is especially the case with General Practitioner medical assessments and the Centrelink controlled health care or other related benefits where chronic mental health issues are involved.

Over the years our adult son has been, and continues to experience general health problems, both physical and mental (depression and anxiety) and all that goes with these conditions. The mental health issues give rise to severe functional limitations with difficulties in managing routine daily activities and accessing essential health, welfare and employment or social support/accommodation services.

In our case our son's medical and mental health conditions have been debilitating and have forced him out of the security of the regular workforce. This has compounded problems of anxiety and self esteem. He is obliged to have continuing health treatments, both physical and mental, which all come at a cost to both him

and his carers. In his case the problems are compounded by the absence of any form of co-ordinated medical support and treatment plan or secure income.

From our point of view there seems to be no evidence of co-ordinated case management or continuity in medical/mental health support. This detracts substantially from the outcomes. Both the person being cared for and the carers are under constant pressure. There seems to be little or no light at the end of the tunnel.

Lack of continuity in the GP medical support presents real problems. Neither the principal patient nor the carer know where things stand at any particular point in time. Often the medical and support processes are seen as being dysfunctional. Those in need of care are frequently left floundering - not knowing where to turn or have to access or finance the essential medical and psychological support services.

From our experience/observation at the GP level "medical confidentiality" is used in such a way that carers are without access to information vital to the performance of their caring role. The advent of large general practice medical centres with frequent changes in GPs and long waiting times does little to assist.

Rarely in assessing the patient does the GP provide a co-ordinated assessment of both the medical and psychological issues. Likewise, it seems rare that either the patient or the carer is provided if any form of treatment strategy or critical review points.

Details of the psycho-pharmacological components and psychological interventions either in terms of prescribed medications or counselling, are conspicuous by their absence. Cognitive behavioural therapy and mental health services available to the individual are inevitably missing from the equation. When the feedback is provided it is difficult to comprehend either by the patient or the carer.

Often it seems the GP intervention is limited to treatment of the conditions/symptoms displayed rather than the primary cause. This is extremely frustrating to both the person being cared for and the carer. Apart from being demoralising this approach is wasteful of resources. It fixes nothing. Often it creates problems. Some medications carry side-effects which can further detract from the quality of life.

Additional comments reflecting personal experiences with and observation of the GP and specialist medical providers have been detailed in Annexure "A".

Clearly, medical assessment/diagnostic skills need to be better developed at the general practitioner levels, if mental health problems are to be appropriately identified to enable early and full intervention to treat the primary cause rather than secondary outcomes of that cause. These improvements are essential to the patients' full recovery and to ease the carer workloads, frustrations and financial pressures.

Financial pressures (stress) caused through the decline in bulk billing facilities and the need to access high cost specialist support services serve to place additional stressors on both patients and carers. The bulk billing arrangements require urgent review. Incentives need to be built in to the arrangements in such a way as to encourage wider participation by both GPs and specialist medical or psychological service providers, especially in the areas of mental health treatment.

We feel, and accept, that our role as aged parent carers is to provide primary care and support the GPs and specialist health care strategy. In our case this support role has been constant over 12-15 years. By necessity it has been in various forms - social, health (physical - mental - dental) education and financial support. This comes at high health and financial cost to the carer, especially those of senior age and fixed income.

Prior to taking up our carer role we had been able to contribute substantially to the broader Australian society through participation in various community based programs. These activities provided focus on aged care and welfare of Australian Defence Force veterans. We also had direct interest and participated in "Riding for the Disabled" and youth group development programs, such as the National Work Skills Olympics and Australian Air Force Cadets.

These community activities have been consumed by our care role supporting our adult son and more recently the working parents of a young grandson. In combination we now find ourselves to be severely stressed both time-wise and financially.

Since taking up our family carer roles we have been obliged to substantially reduce our involvement in all community activities. We have been also obliged to strictly limit social contacts outside our son and immediate extended family.

While we readily accept our responsibility as a parent and carer, we are unable to experience the same freedom of choice available to others in the broader community. But this would be a small price to pay if we could see light of any form at the end of the tunnel.

At this point our choices are substantially determined by the day-to-day needs of our adult son. We have little or no control over these or the costs involved. At times this can cause frustration and stress.

For some time we have been experiencing general and mental health problems and financial stress. We are also time poor - the days are simply not long enough. We have difficulties in providing the level of care and daily support, both real and financial, that we believe our son requires and is entitled to, but is unable to access as part of, what appears to be, an unco-ordinated health and welfare strategy.

As things stand, the bottom line is that we have little or no real social life, outside of daily contact with our son, and are now struggling, like many other carers, financially. We have been obliged to sacrifice the paid workforce and are dependent on a single superannuation-based pension income. Cash reserves have been consumed and continue to be consumed at a fast rate.

Realities of life are that as 74-year old carers with permanent and deteriorating health problems and limited financial resources, neither carer is likely to be able to return to paid employment either part or full time. One carer had continued in part-time employment until age 69 when health problems forced change.

As carers we continually worry about both our health and financial security in context of our ability to continue supporting our son. Apart from our ability to sustain the present level of support, we hold serious concerns with the support

arrangements available to our son and his ability to access these services after our death.

Unless there is a break-through in his medical/mental health treatment program which enables him to re-establish the security of the paid workforce there is a real risk that he will find himself forced to the fringe community without the security of accommodation. At this point we, as the principal carers, provide the essential accommodation and related services that enable him to retain some level of self-esteem.

Our principal concerns are with the limitations of our personal and financial support required to ensure that our son receives the full range of medical/mental services, including dental services essential in providing a reasonable quality of life with long-term security in accommodation.

Financially, we see little or no real relief. We are without the "magic wand". Problems in increasing health/dental costs are being compounded by general living costs (accommodation - utilities - food and personal). With these rising costs retention of modest accommodation and life style is no longer sustainable by either the cared or the carer.

Government unemployment, disability and support pension rates are inadequate. Substantial private supplementation is required by the carers to enable the person in need of care to maintain even the most basic level of independent living that is so necessary to health, self esteem and general wellbeing, both in the short to longer term.

Our situation as a carer is unlikely to be eased until the support arrangements at the national level can be improved. They need to be reviewed to ensure that the support reflects the realities of the spiralling costs of living, including those aspects of health/dental and accommodation essential to wellbeing and to avoid, in the extreme cases, homelessness or increased demands for public housing.

Support services need to be established and eligibility processes developed to provide flexible and readily accessible support. These need to ensure individuals with mental health problems or disabilities do not fall through the gaps and are able to maintain their self-esteem in a safe and secure living environment as part of the broader community.

We are of the firm view that we could survive as carers if the financial stress of providing direct health/dental care and living could be in some way reduced.

It is imperative that the full range of general and mental health services, including dental health, be reviewed with the aim of providing more flexible access arrangements while recognising the individual's differing needs. Clearly this needs to be "balanced" against the individual's self esteem/dignity and the need for through life security. This is a critical balance and will not come without cost.

As things stand, the present arrangements, for both the cared and the carer, lack flexibility and fail to reflect the realities of cost. They do not adequately provide for access by those experiencing chronic general or mental health and related living problems.

GP health service providers need to be provided with broader delegated authority to assist individuals access the full range of essential health services and pharmaceutical support required to provide a reasonable quality of living with the best chance of recovery.

Improvements in those fundamental policy areas affecting the wellbeing of the person in need of care will, for the most part, ease the financial and health stress of the principal carers.

Inevitably success in the former will lead to success in the latter. Clearly changes are needed; these need to be made sooner rather than later if carers are to be provided with better support.

Yours sincerely,

**Kathleen and Arthur**

**Attachment:** 1. Carer's Observations and Perceptions - Mental Health Assessment and Treatment Processes

c.c. CEO - CARERS ACT: Churches Centre, Benjamin Way, Belconnen ACT 2617  
For information

1 July 2008

## **CARER'S OBSERVATIONS AND PERCEPTIONS - MENTAL HEALTH ASSESSMENT AND TREATMENT PROCESSES**

Primary (General Practitioner) and secondary (Specialist - Psychologist - Psychiatrist) medical and mental health care arrangements are in urgent need of review. Achievement in this area will be a pre-requisite to better support for Carers.

As things stand, the fragile and vulnerable in the community are at risk with carers stressed. There is little or no evidence of co-ordinated care planning with clear outcomes.

### **Professional Obligations:**

Both primary and secondary medical and mental health care providers should be obliged to develop and implement collaborative care plans detailing treatments, outcomes and critical review points.

Minimum standards should be applied in the development and maintenance of patients' clinical information. Protocols should be developed to provide for the exchange of patient care plans and related information between medical service providers.

Protocol arrangements should be in compliance with minimum service delivery standards and supported by legislation and Codes of Practice to protect outcomes for patients and ensure best practice for primary care providers.

Clearly effective treatment of depression and anxiety is dependent on early intervention, based on accurate assessment diagnosis with evidence based care plans to suit individual patients.

### **Assessment and Diagnosis - Co-ordination and Care Plans:**

Primary health and mental health assessment/diagnosis and care/treatment plans must be co-ordinated at both the medical and psychological levels with full exchange of information between both levels involving all care providers.

Collaborative care plans, with treatment strategies and essential review points, to achieve effective short and long term outcomes to benefit the patient and indirectly the carers are lacking and should be mandatory.

### **Treatments:**

To have any reasonable chance of success and effective benefit for the patient, primary mental health care and treatment should be co-ordinated at both the medical and psychological levels with information between the two levels, the patient and the dedicated care providers. There needs to be a clear understanding of the scope and nature of the care plan and the outcomes likely to be achieved along with details of perceived risks.

Psychological therapies developed against the "care plan" should be established in consultation with the primary GP service provider, the specialist level provider and the patient.

Psychologists/Psychiatrists should be obliged to base therapies on proven treatments and pharmaceutical materials. Unproven and high cost treatments of related thyroid conditions and extreme depression/anxiety conditions should be avoided.

### **Review Points:**

Generally, the mental health treatment system should be obliged to seek quality outcomes in terms of critical review points for both primary and secondary care/treatment of chronic mental health conditions with full patient information being made available to **all** health service providers including the patient and carers.

### **Perceived Problems:**

Despite changes with new additional item numbers being established within the Medicare Benefits Scheme and the focus now providing for improved GP intervention in mental health care through the National Chronic Disease and National Mental Health Strategies, it would seem that our most vulnerable will continue to be lost in the system.

There is evidence to suggest some GPs appear to want to side-step diagnosis/assessment and intervention in the delivery of mental health services. We see instances where the GP will either seek to treat the symptom rather than the cause or they simply make referrals to the likes of psychologists.

Unfortunately, there are some working in this profession who seem intent on "experimenting" with unproven high cost thyroid treatment processes involving suspect pharmaceutical compounds without any form of consultation with the primary medical GP. In this case the consultation had

been left solely to the patient who was most vulnerable with chronic depression/anxiety.

To avoid the high level of patient risk, there is an urgent need for early intervention with co-ordinated treatment against care plans with follow-up monitoring of the patient by both the general practitioner and specialist medical providers. This should be a mandatory process, particularly where chronic mental health issues are involved and patients are at their most vulnerable.

Clearly, quality medical outcomes will be dependent on quality of feed-back from specialist health providers including psychologists to the primary GP level. This interface is in urgent need of review and improvement.

From our experience, we have seen incidents of either delayed or, in some cases, wrong or inconclusive diagnosis. There have been incidents of unco-ordinated treatments involving high cost unproven pharmaceutical compounds. Inevitably this gives rise to loss of confidence/anxiety for both the person experiencing the chronic illness and the carer.

#### **Future Options:**

There is an urgent need to improve the quality and control the costs of general medical and mental health treatments delivered against co-ordinated treatment plans. Costs of both diagnosis and treatments flowing through to and being, by necessity, absorbed by carers need to be controlled. Without control financial stress/anxiety will be imposed on those receiving treatment and those involved in the carer process.

Quality mental health outcomes will be dependent on development of collaborative assessment/diagnosis processes and the dissemination of multi-disciplined care plans that take into consideration **all** health care providers and the patient along with acknowledged carers.

There would seem to be a case for Federal and State/Territory governments to seek to work in concert with the Divisions of General Practice to establish priorities in the delivery of mental health services. Principal aims should be to improve governance, professional and financial accountability.

Outcomes should seek to establish early intervention and improve:

- ◆ the assessment and diagnosis processes;
- ◆ access to treatment and support services;
- ◆ broaden bulk billing arrangements for mental health/chronic depression and anxiety;
- ◆ management of chronic mental and related health conditions.

Considering the level of Commonwealth recurring funding support to the Divisions of General Practice, the Government should seek to influence, more



directly, outcomes against the Multi Program Funding Agreement by setting more specific targets and benchmarks.

**Conclusions:**

Until specifically targeted outcomes are defined our most fragile and vulnerable health service consumers are likely to continue to fall through the cracks. They will be marginalised in the community. Their security and wellbeing will be at significant risk, particularly where family carer intervention and support is no longer available.

If improvements are to be achieved in the delivery of mental health services to the most vulnerable in our society and the carers who support them, the Department of Health and Aging will need to have a very much stronger intervention role in influencing the Divisions of General Practice's strategic thinking and accountability in the development/delivery of primary mental health care programs.