



Carers' Checklist

An outcome measure for
people with dementia
and their carers



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CARERS' CHECKLIST - USER GUIDE

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INTRODUCTION

The Carers' Checklist is an easy-to-use measure which can be used to assess the needs of people with dementia and their carers, and to evaluate the outcomes of service intervention. It has been developed through work with carers of people receiving specialist dementia services and carers seeking support from voluntary groups.

The checklist is normally used as a self-completion questionnaire, taking about 15 minutes for a carer to complete. However it can also form the basis of an interview, or act as the focus for a discussion.

The Carers' Checklist can be used in the following ways:

- to assess the extent of dementia-related problems, including cognitive symptoms, problems of daily living and social functioning
- to assess the burden of care, including social, financial and physical demands, in terms of the carer's own experience
- to monitor changes in the needs of patient and carer over time
- to evaluate the impact of service provision on carer burden and carer satisfaction, both for individuals and for groups of service users.

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1 OUTCOME ASSESSMENT

1.1 MEASURING OUTCOMES

The current health care climate places pressure on services to evaluate the effectiveness and efficiency of interventions. In the UK, the Government White Paper Working for Patients required that each health district have some system of audit.

Audit itself is seen as a cyclical activity with three stages¹:

- observe practice and see what is happening;
- compare this against standards;
- implement appropriate change.

In the health-care context, outcome is usually defined in terms of the achievement of, or failure to achieve, desired goals. In simple terms, outcome has been described as the result of interventions. Measuring the effectiveness of interventions is important because it allows the evaluation of services and can improve quality. This information can be useful for purchasers and providers of services.

1.2 MEASURING OUTCOMES IN DEMENTIA SERVICES

Although improved outcomes are a fundamental goal of the health service, outcome measurement has rarely been incorporated into routine practice. The ability to measure outcomes and assess service efficacy has been particularly limited in the field of dementia. Outcome measures need to capture the complex input of care required for someone with dementia. Many people with dementia rely on informal carers, and outcome measures need to also capture carer well-being.

Outcomes need to reflect the aims of the service and the needs and expectations of service users. A systematic literature review and survey of health professionals and carers identified the domains of functioning relevant to both the person with dementia and the carer² (see Table 1).

Table 1: Important domains for dementia services

For the person with dementia
Improve physical well-being (<i>e.g. mobility</i>)
Improve psychological well-being (<i>e.g. depression, anxiety</i>)
Maintain social functioning (<i>e.g. ability to communicate</i>)
Ensure safety
For the carer
Improve psychological well being (<i>e.g. depression, anxiety and stress</i>)
Improve knowledge and skills (<i>e.g. about diagnosis, behaviour management</i>)
Improve social functioning (<i>e.g. social support, free time, respite</i>)
Improve satisfaction (<i>e.g. access to services, co-ordination of services</i>)

2 BACKGROUND OF CARERS' CHECKLIST

A systematic review of the literature³ showed that there was no measure available which addressed all of the important domains of dementia services, for people with dementia and their carers. The Carers' Checklist was developed as a response to the need for such an outcome measure, feasible for use in routine practice. The measure is based on three standardised measures: the Problem Checklist⁴, The Support Team Assessment Schedule⁵, and the Behaviour and Mood Disturbance Scale⁶.

2.1 OBJECTIVE AND SUBJECTIVE BURDEN

The Carers' Checklist is based on the theoretical model of objective and subjective burden. Objective burden relates to the frequency of dementia-related problems (i.e. severity of dementia), while subjective burden is the carer's interpretation of how stressful they find each problem to cope with. This is an important distinction to make, as severity of dementia is not necessarily correlated with carer burden. Some carers cope well with many problems, while others may find one or two problems difficult to cope with⁷.

The Carers' Checklist contains a list of dementia-related problems which may occur. Column A asks how often the problem applies to the person being cared for ('never'; 'sometimes'; 'always'); and Column B asks how stressful carers find each problem to deal with ('not stressful'; 'quite stressful'; 'very stressful'). Carers indicate their response by placing a tick in the boxes which best describe their situation.

The second part of the Carers' Checklist consists of 5 scales relating to overall burden, physical burden, financial burden, emotional burden, and social burden. Carers rate how burdensome they find caring on each of the 5 scales by circling the number from 1 (no burden at all) to 5 (a great burden) on the line, indicating the number which best describes their situation.

2.2 DOMAINS COVERED BY THE CARERS' CHECKLIST

The Carers' Checklist includes items relating to the following domains of functioning for both the person with dementia and the carer:

For the person with dementia:

- Cognitive symptoms
- Psychological symptoms
- Activities of daily living and self care
- Inappropriate behaviours
- Social behaviours
- Safety issues

For the carer:

- Social burden
- Emotional burden
- Physical burden
- Financial burden
- Burden of specific dementia-related problems
- Satisfaction with services: access, co-ordination, information

2.3 ACCEPTABILITY, RELIABILITY, VALIDITY

The acceptability of the Carers' Checklist to both staff and carers has been assessed⁸. All staff felt that the measure applied to their service and that it was a useful tool in both assessment and outcome. Carers felt that it was useful for them to complete the questionnaire as it gave them the opportunity to express their views. Carers felt that the questionnaire was relevant to their caregiving situation.

The three original scales from which the measure was devised have been proven to have good reliability and validity, and to be sensitive to change over time. The Carers' Checklist has good internal consistency (Cronbach's alpha = 0.93). However, further data is needed on sensitivity to change over time.

2.4 CREDIBILITY

The Carers' Checklist has been used with carers of people referred to specialist dementia services (old age psychiatry teams) and with carers known to voluntary organisations. Most of the carers known to the specialist dementia services were caring for people with quite severe stages of dementia. However, those in touch with the voluntary services were experiencing a wide range of severity.

The Carers' Checklist is designed for current carers, of people with dementia. The measure has mainly been used with English-speaking carers. The validity of the measure as an interview with interpreter has not been assessed.

2.5 LENGTH OF ADMINISTRATION

In a study examining the use of the Carers' Checklist in routine practice, the average completion time was 15 minutes. Completion tended to take longer when staff were present and carers took the opportunity to discuss some of the items with staff, or when staff were using the measure as an assessment instrument at first assessment.

2.6 SETTINGS

The Carers' Checklist has been used with carers of people receiving or attending specialist dementia services (e.g. community services, day hospitals, respite care etc.), and with carers known to the Alzheimer's Disease Society.

2.7 LIMITATIONS OF MEASURE

The Carers' Checklist is not a diagnostic tool. The measure is dementia-specific and should only be used in cases where there is a suspected/confirmed dementia diagnosis.

3. ADMINISTRATION

3.1 WORKING WITH CARERS

There are sensitive issues to be aware of when working with carers. Many questions can be raised while filling in a questionnaire. These may raise anxieties, and prompt discussion. In this way, the measure can be a good tool to aid discussion with carers about subjects which they may not have raised themselves. Completing a questionnaire can be tiring and carers should feel able to stop completing the measure if they do not want to continue, or come back to the questionnaire later.

The measure contains items specifically related to dementia. The instructions have been worded carefully to emphasise that carers may not currently or ever experience all of the problems. However, staff should be aware that carers who are unaware of the nature of dementia may find the list upsetting in terms of problems which may possibly occur in the future.

The two stage process of the questionnaire may need explaining to carers. The instructions give directions of how to complete the questionnaire, but those who are unfamiliar with completing questionnaires may need to check the process. We recommend that carers complete both components (frequency and stress) of each question before going on to the next question.

3.2 METHODS OF ADMINISTRATION

The Carers' Checklist is designed to be a self-completed questionnaire and this is the best method, since carers are able to select their responses without the influence of others. However, in special cases, the Carers' Checklist has also been used as an interview format. This has occurred in situations where carers may have difficulties reading and completing the questionnaire. When providing assistance to carers in this way, it is important that staff try not to influence the carer's responses through their own view of the situation.

Sometimes, people do not feel that any of the available responses describes their situation exactly (for example, the problem behaviour may occur more than 'sometimes' but not 'always'). In these instances, the carer should try to decide which response is the closest to how they feel.

3.3 FREQUENCY OF ASSESSMENTS

Repeating the Carers' Checklist over time through concurrent assessments and comparing scores over assessments can provide useful information about patient and carer functioning over time.

The Carers' Checklist has been used in routine practice at referral to specialist services, after 6 weeks, and after 3 months. These time periods were negotiated with clinicians who felt that this would provide a clinically relevant period of change.

It is up to individual services to decide when assessments should be carried out. The important point is that assessments are made when it most makes sense, after a period has passed in which change may well have occurred, and when it is not so soon that the carer feels fatigue and burden at completing the measure again.

4 SCORING

4.1 SCORING THE CARERS' CHECKLIST

Each of the individual items in the first section of the Checklist is scored in the following way:

Column B:	never = 0,	sometimes = 1,	always = 2
Column C:	not stressful = 0,	quite stressful = 1,	very stressful = 2

Total frequency of dementia-related problems is calculated by adding together all the items in Column B. There is a possible maximum of 60.

Total carer burden caused by the problems is calculated by adding together all the items in Column C. There is a possible maximum of 60.

The carer burden scales are calculated by adding together the scores on all of the five burden scales. There is a possible maximum of 25.

Scoring can be done quite quickly by hand. Alternatively, the use of a database allows more sophisticated analysis of data.

4.2 DATABASE ISSUES

Recording the Carers' Checklist scores in a systematic way in notes may be adequate for the purposes of many services. This all depends on what you are collecting the data for, and what the objectives are.

If an analysis of scores is going to be carried out a database will be helpful. A simple spreadsheet (such as Microsoft Excel) is one simple way of managing data. It can be used to enter scores from the Carers' Checklist, and will enable you to calculate scores, draw graphs etc. from the data. A good computer manual (e.g. of Excel) will prove invaluable.

More advanced software packages are available which have facilities for carrying out a wide range of statistical tests (for example, SPSS). Such software is only necessary if intending to carry out statistical analysis of data.

5 ANALYSIS

Data from the Carers' Checklist can be analysed by looking at individual cases, or by looking at groups of cases.

5.1 ANALYSIS OF INDIVIDUAL PATIENTS/CARERS OVER TIME

The scores of individual patients/carers can be analysed over time. This is useful for looking at how individual situations have changed, and whether interventions may have been effective. Raw scores can be compared over assessments. Individual items can be examined in terms of the problems which may have arisen since last assessment. This could be useful in terms of planning care for the next intervention period.

5.2 ANALYSIS OF GROUPS

Analysis of groups can be useful in terms of looking at the overall effect of interventions on patients/carers referred to services. For example, you may want to look at a group of patients/carers who have been referred to the service over a certain time period.

Group analysis also allows you to look at the role of other factors on scores. For example, you may want to look at problems in relation to a particular diagnosis; or look at those patients who are living with a carer etc. This type of analysis is useful for a small scale service research project, and for analysing those groups of patients/carers most at risk. Group analysis usually requires the use of a database to manage the data, as discussed above. Statistical advice may be required.

5.3 INTERPRETATION OF RESULTS

It can be useful to compare results with those from other studies gathering similar data. Our studies of carers known to specialist dementia services and those known to the Alzheimer's Disease Society have shown that carers vary widely in their response to the Carers' Checklist in terms of the number of problems they experience, and the related burden. Some carers report few problems, while others report many. Although the majority of carers experience burden, a few report very little burden.

The ranges of scores we have found in our studies of 120 carers are displayed in Table 2. Other studies have found similar levels of problems.

Table 2: Range of scores on Carers' Checklist from 120 carers

Scale	Range of scores	Mean	SD
Frequency of dementia-related problems (maximum score of 60)	5 to 56	23.37	10.91
Carer burden of dementia-related problems (maximum score of 60)	0 to 53	18.30	11.19
Carer burden scales (maximum score of 25)	8 to 25	17.00	5.9

In terms of carer burden, our studies have indicated that over 70% of carers find caring a burden emotionally, socially, physically and overall. Up to 50% find caring a burden financially.

A certain amount of burden related to caring is inevitable, as a response to the chronic stressful situation of caring for a loved one. However, prolonged high levels of burden can have negative effects on carers' physical and psychological health. We have found that a substantial sub-group of carers are experiencing problems and high levels of related burden. Services may want to target this vulnerable sub-group of carers.

Services may want to look at the service-related items of the Carers' Checklist separately. These items can produce interesting results with implications for services related to access, information, and co-ordination of services.

5.4 PRESENTING RESULTS

Results can be presented in a number of ways. Simple numerical results of scores can be used. Graphic representations which show changes over time, such as line graphs mapping assessments, can be useful. Tables and graphs, such as bar charts, can be used to illustrate differences between groups.

The following two case studies illustrate how the Carers' Checklist can be incorporated into routine practice and used to explain how the situation can change over time for both the person with dementia and their carers.

Case study 1: Mr A

Mr A was referred to the specialist service in July 1996. He is a white male, age 70 years. He has been diagnosed as having Alzheimer's Disease, with onset of symptoms at the age of 67. Mr A also has osteoarthritis in his hip. He lives with his wife who is retired. She has no significant health problems.

At referral, Mrs A was providing informal care such as shopping, cooking and housework. Mr A's symptoms were quite mild at referral, with the total frequency score being 6. Mrs A was coping well with these problems and the total burden score at referral was 5. Mrs A reported that she found caring no strain at all physically, financially, socially, or overall although she reported that she found caring a moderate strain emotionally. She said she would like more information about medication. She felt that services were not working together to help her.

By the time of the second measure, six weeks later, Mr A's condition had deteriorated rapidly. The total frequency score was now 52 with the cognitive aspects, psychological factors, physical abilities and activities of daily living all being rated as frequent problems. The burden score had also increased to a total of 30, although this increase was not as dramatic as the frequency score. Mrs A found the behaviours related to psychological factors such as temper outbursts, anxiety and restlessness particular problems. Mrs A felt that services were now working together to help her. Mrs A reported that although financially and socially she did not find caring a burden, she now reported that physically it was more of a problem and she found caring a greater strain emotionally. Her informational needs in terms of medication had now been met and she wanted information regarding financial matters.

Mr A was now attending a health services day centre and Mrs A was receiving the care of a carer support service.



Case Study 2: Mr B

Mr B, was referred to the multidisciplinary team in January 1996. He is a white male, aged 77 years. He has been diagnosed as having Alzheimer's disease with the first signs of onset occurring when Mr B was 70. He has no other significant health problems. Mr B lives with his wife, who is 74 years old. She has had two hip replacements and is waiting for a knee replacement.

At the time of referral, Mr B was attending a day centre one day a week, run by a voluntary service. Mr B and Mrs B were receiving no other formal services.

At referral, the main problems reported were cognitive, such as Mr B forgetting what had happened and always asking questions. Personality clashes were occurring, with Mr B sometimes being rude to visitors, and caring was disrupting his wife's social life. Mr B himself often wandered at night and was often restless, anxious and agitated with occasional sudden mood changes. Mrs B reported many aspects of caring as being difficult to cope with and these were related to the frequency of the problem behaviours, although she found the sudden mood change and demanding attention particularly difficult. Mrs B reported she found caring for her husband a great strain physically, emotionally and in terms of social life. She did not feel that services were working together to help her.

By the time of the second measure 6 weeks later, Mr B was still attending the voluntary services day centre, now twice a week, and was also attending a health services day centre once a week. A community psychiatric nurse was involved and Mrs B was attending a carers group. Mrs B now felt that services were working together and her informational needs had been met. Mrs B was still responsible for the finance, housework, cooking, shopping and bathing Mr B. At follow up, the frequency of problems had reduced dramatically. Mr B was less anxious, although still often restless and wandering at night. The cognitive aspect of forgetfulness was still present. Mrs B no longer reported Mr B's behaviour to be creating personality clashes or disrupting her social life. The total frequency score had reduced from 32 to 10. Mrs B also reported an improvement in her ability to cope with caring for her husband. The total burden score reduced from 33 to 10 although she still found the restlessness, forgetting and wandering at night particular problems. She reported that physically, emotionally, socially and overall, she found caring less of a strain and was better able to cope.

6 ADDITIONAL INFORMATION

6.1 ADDITIONAL FACTORS TO RECORD

Any measure which is short enough to be used in routine practice will yield limited information. The Carers' Checklist contains just a few items relating to each of the important domains of dementia services discussed earlier.

Background data such as basic demographics for the person with dementia and the carer can be useful to collect. Such data can be useful to examine in relation to group differences in scores on the Carers' Checklist, as discussed earlier.

The Carers' Checklist focuses on the problems which carers experience, and related carer burden. Positive aspects of caring, which carers may experience, are not included in the measure and could form part of the assessment. A full assessment of carer well-being may also include a measure of carer coping (e.g. Carers' Assessment of Managing Index¹⁰); and psychological distress (e.g. General Health Questionnaire¹¹).

6.2 FURTHER DEVELOPMENT OF THE MEASURE

The Carers' Checklist is subject to ongoing development. The measure has been developed to be acceptable to staff and carers for use in routine practice, but the robustness of the measure in terms of sensitivity has not been examined in detail. Further assessment is needed of the sensitivity of the measure to assess change over time.

The development of culturally-sensitive items would be both useful and important. Any new items would need to be assessed for acceptability, reliability and validity.

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Carers' Checklist

APPENDIX



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Column A

Behaviour

- 17 Unable to manage stairs
- 18 Not safe if outside the house alone
- 19 Cannot be left alone even for one hour
- 20 Wanders about the house at night
- 21 Careless about own appearance
- 22 Unable to dress without help
- 23 Disrupts my personal social life
- 24 Unable to wash without help
- 25 Sudden mood changes
- 26 Appears anxious/ agitated/ frustrated

Column B

This applies to the person that I care for:

Always Sometimes Never

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Column C

I find this aspect:

Very stressful Quite stressful Not stressful

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

This applies to me:

Always Sometimes Never

- 27 I need more help from services than I am given
- 28 I need more information than I am given
- 29 Services need to work together and communicate more
- 30 I need better access to services

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I find this:

Very stressful Quite stressful Not stressful

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



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