



Provision for Carers: What do Pain Management Programmes (PMPs) Offer?

June 2004

Thank you for your participation in the above survey.

Ninety-eight questionnaires were sent to PMPs in April 2004. Data were subjected to descriptive statistics and thematic analysis. The results are summarised below.

Fifty-three centres offering 64 PMPs responded. Four deliver inpatient programmes. The remainder offer outpatient PMPs varying in length from 1 day to 9 months, delivered over 7-8 weeks, with an average of 37 hours per programme (range 7-104 hours). 72% of PMPs see patients individually, with half offering 1–12 hours per patient and the rest not specifying a maximum. 53% of PMPs make provision for carer involvement: 4 have an open invitation, 22 offer dedicated sessions and 8 offer both. Programme content for carers was categorised into three themes:

The Patient's Journey: 21 PMPs deliver sessions to carers on the aims of the programme, philosophy of pain management, pain mechanisms and the mind/body link.

Patient Support: 19 PMPs offer carer sessions related to:
Maintaining change - such as recognising pain and pain behaviour, supporting the patient and improving communication.
Skills development - teaching carers how to set goals with the patient, support pacing, stretching, exercise and relaxation and manage anger and medication.

Living with Chronic Pain: 12 PMPs offer carer focussed sessions, telephone contact or facilitate opportunities for carers to mix and socialise with each other. One teaches aromatherapy to carers for their own benefit.

Thirty programmes do not make provision for carers. The main reason is lack of time and resources. Some feel that it is inappropriate to involve carers and, indeed, a small number no longer do so as they feel that attendance is poor and group dynamics are affected. However, 89% of responders believe that carer involvement is important. The reasons given were:

The Patient's Journey: Carers need education and a sound understanding of PMP aims, pain management and pain mechanisms if they are to work with and support the patient.

Patient Support:
Patient Support: The role of carers is viewed as being "essential to promote pain management skills and reduce unhelpful behaviours".
Maintaining Change: Carers have a significant impact on patient outcomes. "If carers encourage helpful habits, it makes the difference between success and failure".
Couple Work: Change only occurs within the family context. Both negative examples, such as the "patient sees the programme as their time" and positive examples, such as mutual support and improved communication, were given.

Living with Chronic Pain:
Practical Help: Enabling carers to express practical needs, seek solutions, guidance and help.
Emotional Help: Carers have their own emotional overlay. "Carers are also victims".

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The themes appear to be located on a continuum from a practitioner orientated rationale, through a family centred philosophy to an acknowledgement of the needs of the carer.

Please contact us if you would like to discuss the results further or would like to know more about our research programme on the impact of chronic pain upon the family/carer. Thank you.

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This summary will also be available at: www.painconsultants.co.uk