

**The Macfarlane Trust
National Support Services Committee meeting 2nd September 2005**

Policy discussions briefing paper

1. Introduction

There are a number of outstanding policy issues awaiting discussion and resolution. These are summarised below, to help stimulate discussion.

a. Motability Grants

It was proposed at the last meeting of the NSSC that, in future, a maximum for all Motability Deposit Grants should be set of £1,000, whatever the circumstances. It was agreed that this suggestion should be discussed at the next meeting of the NSSC before being implemented.

If this is agreed as a maximum, future applications will be dealt with under office guidelines, with applicants requesting more being asked if, with a grant of £1,000 they are able to go ahead with the purchase, before the grant is made.

b. Tempur mattresses

It was noted at the last meeting of the NSSC that there have been a number of requests recently for grants towards a Tempur mattress. It was agreed that funding for these mattresses should be discussed at the next meeting and that guidance should be sought from practitioners and users on how beneficial they are.

Dr Mark Winter has been asked if he has a view on the benefits of these mattresses, his response will be reported at the meeting. A registrant has written a report on his experience of them (see second set of case papers, 1933). Having obtained a discount and a VAT waiver, his mattress has cost £1,155.

Current office guidelines allow for up to £2,500 to be spent on "Equipment for Disability and Special Chairs/Bed", so clarification is also required on whether tempur mattresses qualify under this heading.

c. Expenses and payment for travelling time

In April 2005 the NSSC agreed travelling, subsistence and accommodation expenses for registrants attending hospital, people attending committee and other meetings, and independent consultants ie IFA, counsellors.

As this was a general discussion on expenses it did not touch upon the amount the independent consultants are paid.

I have been asked to raise this for discussion, as the counsellors are currently paid £10 per hour for travelling time, which has been a contributory factor to the high costs of the bereavement group meetings in Manchester and the Bereavement Weekends.

They point out, however, that if they are not paid for travelling time it seriously impacts upon their income, as they can spend a great deal of time travelling on MFT work, which keeps them away from other paid employment

Recommendation

That this matter be postponed until the new bereavement group recommends services to be provided.

That the counsellors be informed that, if the Manchester Group does meet again, only one counsellor will be paid to attend and no overnight accommodation will be provided.

d. Respite grants

At the NSSC meeting on 4th May 2005 it was agreed that a recommendation would be made to the Board that:

- i. all registrants and infected intimates not living with a registrant be awarded an annual payment of £750 during the first half of the year, to enable them to arrange a holiday
- ii. respite grants be removed from the office guidelines
- iii. before any request for a respite break is considered by the NSSC, it should be supported by a specific recommendation from a medical practitioner that they believe a respite break will improve their health.

This was agreed at the Board meeting on the 18th July 2005. When the letter was sent to registrants informing them of the summer grant, however, it stated 1) All applications for respite breaks will have to be considered by the National Support Services Committee and before any decision can be considered by that committee, it must be supported by a specific recommendation from a medical practitioner that they (the medical practitioner) believe a respite break will improve an individual's health.

There were a number of applications "in the system" at the time of the change. There are also registrants still applying for respite grants and are surprised and often angry when they receive the reply agreed by the NSSC stating:

"The main reasons for this were that you can use the £750 summer payment awarded 20th July towards this expense, and that your doctor's recommendation ***did not refer to any specific medical incident or hospitalisation leading to a need for convalescence.***".

Social workers and consultants who provide supporting letters have also expressed unhappiness at the change in policy being brought in without prior announcement. I have attached correspondence from a social worker regarding this (A) but have received more and some much stronger verbal complaints.

Recommendation

That respite break grants cease.

That convalescent grants be introduced.

That the maximum award be £750.

That doctor's recommendations should refer to a recent, specific medical incident (eg infection) or hospitalisation leading to a need for convalescence.

That up to two convalescent breaks a year be allowed under office guidelines, where the above criteria are met.

That any requests for larger amounts or for more than three grants in a year be referred to the NSSC.

That the respite policy agreed be circulated to all registrants, and to all directors and social workers at haemophilia centres, as a priority.

e. Notification of other grant-making policies

The Kingston Smith report on the Trust's grant making procedures benchmarked us against best practice guidelines. To quote from page 11 of the report:

"Literature and application forms should be clear and user friendly and should include the following information:

- *What the trust will and will not support...*
- *Any upper or lower limits on grant size"*

It has been agreed more than once at the NSSC that the Office Guidelines should be confidential and staff should not tell registrants that they exist. We are, therefore, clearly not complying with Kingston Smith's recommendations. As well as being a question of best practice, however, the current policy of not informing registrants of grant-making policies is leading to unfairness and causing unhappiness and extra stress for registrants.

I have attached (B) correspondence from registrants regarding this, but have had similar views expressed verbally by many others.

Unfairness

The office guidelines are not a complete secret, I have had them commented upon in detail by a registrant who says he has a copy that came via "the hacker". Other registrants are finding out how much they can apply for by simple trial and error, applying and seeing how much they get. This kind of information spreads via networks and the website bulletin board.

There are, therefore, some registrants who know exactly what they can apply for. This puts them in a position of advantage when compared to others who do not and leads to a situation where there is no consistency or fairness in who gets grants and who doesn't. Only those who ask get grants, and the fact that they ask is not an accurate measure of need: some people may be in desperate need but not ask because they do not realise they can apply for that type of grant.

Unhappiness and extra stress

In my experience, when people find out belatedly that they could have asked for assistance in the past but didn't because they didn't know, they become angry. "Why didn't you tell us we could apply for a ...?"

If we do not tell people what they can apply for but simply say they should apply, we build expectations and they can be angry when turned down. "Why didn't you tell me I was wasting my time applying?"

Similarly, if we tell people what they can apply for but not how much, it can be even worse. "Why won't you give me enough to afford to buy it? You agree I need it, but won't give me enough for it."

If a registrant puts effort into applying for one grant and is turned down, they may not apply again for something that would receive funding.

For some of our registrants applying for a grant is a stressful experience, and it should be as simple and straightforward as possible. The more ill they are, the easier it needs to be.

Potential difficulties

Some members have in the past expressed the view that advertising the office guidelines will lead to a massive call on the Trust's resources as people apply for everything they can. There is not, however, any evidence to support this.

For example, on three occasions recently people have applied for loans and, when told they could apply for grants instead, have said they do not want grants, they just want a loan. It is also clear that people will not apply for a grant for a washing machine just because it is available, if they do not need a washing machine.

There will obviously be an increase in demand if the guidelines are published because people who are in need that at present do not apply, will be encouraged to. This does not, however, seem a bad thing, since we are possibly not meeting the needs of some of those registrants most in need: the ones who are relatively isolated and not in contact with others to find out what they can apply for.

One way of ensuring the Trust does not generate demands it cannot meet, however, is to start small by giving a limited list of grants that can be applied for. Monitoring requests over a period of months will show whether the fears are well founded and, if they are not, enable the committee to add additional things to the list.

Recommendation

That a core list of grants be agreed that will be fully publicised to registrants.

It should contain information, including maximum amounts that can be claimed, on:

- Prescription pre-payment certificates
- Hospital fares
- Assisted conception costs
- Assisted conception ancillary costs
- Respite grants
- Motability grants
- Non-motability transport grants
- Domestic appliances

Demand to be monitored and reviewed by the NSSC after six months,

Jude Cohen
Head of Support Services
25 August 2005