Mid North Palliative Care Referral and Care Planning Project.

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Government of South Australia

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Introduction

The Mid North Palliative Care Referral and Care Planning Project (MNPCRCPP) was an 18 month project which was completed in June 2008.

The project focussed on the Mid North Health Area of South Australia and was conducted by a project officer – ***Jane Keeley***, as part of the Port Pirie Palliative Care team.

The project has contributed to the improvement of services to the palliative care population of the Mid North health Area of South Australia.

It has the potential to be replicated within other regional and rural areas to improve palliative care services.

Main project activities implemented

Memorandum's of Understanding

- Memorandums of understanding (MOU) were developed and endorsed, enabling clear definition of service providers roles and level of service provision. The MOU's provide the necessary infrastructure to enable future planing and development of Palliative Care service provision for the Mid North Health area.
- MOU's exist between primary generalist providers (regional health units and Residential Aged Care facilities in the Mid North Area of SA) , primary specialist provider's (Port Pirie Palliative Care service) and specialist palliative care provider (Royal Adelaide Hospital).

Main project activities implemented

Patient Diaries

Clients have a resource which enables them to increase control and participation in their health care and support the smooth transition between settings of care in the Mid North Health area. The patient diary has been evaluated and modified , and is now available for clients diagnosed with cancer or a terminal illness.

Main project activities implemented

Care planing/referral flow charts

The development of flowcharts has lead to improved collaboration between services providing palliative care. There now exists a documented flexible regional referral and care planning process to meet the needs of palliative care clients.

This infrastructure has ensured clients have access to level 1 and level 3 palliative care specialist services to meet their palliative care needs.

Main project activities implemented

The *"Mid North Palliative Care Resource Guide"*

- Definitions, Standards for providing Quality Palliative Care and Palliative Care Phases
- Referral process for Palliative Care services in the Mid North Health Area
- Port Pirie Cancer Support and Palliative Care Referral Form
- In Home Management Plan
- After Hours Support for Regional Primary Health Care Professionals
- Assessment and Care planning for Regional Palliative Care clients
- Dictionary
- Useful Resources

Resources developed.

The following resources were developed as part of the project and can be obtained by contacting the Port Pirie Palliative Care Service.

- Patient Diary
- “In Home Management plan” form
- Referral Process for Palliative Care Services in the Mid North Health Area flow chart
- After Hours Support for Regional Primary Health Care professionals flowchart
- Assessment and Care Planning for Regional Palliative Care clients flowchart
- Palliative Care Clinical Pathway and Resource Folder
- Laminated symptom control pathways

Evaluation findings

Evaluation

There were four individual surveys distributed to Fifteen ***Primary Health Care professionals*** in the Mid North Area focusing on the patient diary, Mid North Palliative Care Resource Guide, "*After Hours Support for Regional Primary Health Care Professionals"* and the *"In home management plan"*.

The limitation of the results were due to the low number of Palliative Care clients in the Mid North health area during the project period

Evaluation

Patient diary:

Primary care providers in the Mid North Health Area were surveyed with a low number having actually having used the diaries. Those that had responded that the diary had improved communication between service providers and was helpful to them as a health professional.

10 General Practitioner clinics in the Mid North Health area were initially each provided with 10 client diaries.

Many months after original diary distribution each General Practitioner clinic was phoned and the receptionist was asked if they were familiar with the cancer support/palliative care patient diary and how many dairies were left.

Six clinic receptionists were familiar with the patient dairies. Nine clinics had given out a diary. One had not but this was because they had not had any cancer support or palliative care clients.

A survey was also sent to the twenty six General Practitioners with a 58% Response rate. The result findings indicated that the diaries were being distributed by the GP's .

> Approximately 20 Clients or carers who were using or had used the diary as part of their care were identified .Seventeen consented to the face to face interviews. The key finding was that the diary did improve client care and communication with service providers.

What the clients said!

Did you use your diary?

- Yes
- Commenced using the diary, but didn't follow through.
- I received the dairy sometime after had started treatment. I had already started another notebook and I did not want to transcribe all the information
- No XX got sick so quickly and I had to concentrate on him and not filling out the diary

Do you think the diary helped improve communication between Health professionals involved in your care?

- One GP did not write in it and another GP, would write everything in the diary at each visit
- Never really said took it to Adelaide appointments but not to appointments with the local GP was a very private person so did not to use it to record some things for everyone to look at
- Yes - as I can forget things and for example if I give it to Dr XX he can see what the other Dr's say and what medication I am on

- **Between yourself and the health professionals?**
- It was certainly easier having the information written down then having to explain it to the health professionals as did not want others to talk for him.
- Yes I brought it in for the chemo nurse to see

- **Between yourself and your family?**
- Yes when they came home they would read it.
- Yes it was very helpful as the family could read the diary as they did not live in Pt Pirie.
- Yes it would have been better if I could read their writing
- No family didn't acknowledge XX was so sick and therefore did not look at the diary.

What the clients said!

Did any health professionals write in your diary?

> Yes local GP, palliative care nurse, chemotherapy nurse, dietician, Palliative care staff, and surgeon.
> Yes Palliative Care Specialist wrote in the diary information for local GP and to show family.
> Dr Z wrote in the dairy when XX had to stay overnight in hospital following chemo that he could go home the next day

Did you take your diary to doctor appointments?

> Yes local GP, palliative care nurse, dietician, and surgeon.
> No forgot to take it with me I write in it when we get home
> Yes we carried it every where, it had all of Medications recorded in it
> No not to the local GP but did take it to appointments in Adelaide

Did the doctor, nurses or staff read your diary?

> I think the nurses did, I don't think the Drs did.
> Yes when being admitted to hospital so I didn't have to repeat the NOK information and medication info
> Yes the outreach nurse looked at it daily, the local GP looked at it every home visit, the carer would leave messages for the GP eg scrips low, pain control inadequate or to report any other symptoms
> If I presented the dairy the Drs looked at it. The acute nursing staff did not look at it
>

Do you remember any comments made by your family/carer/doctors about the diary being useful?

> One local GP said he did not know what the diary was for and the other local GP thought it was a really good idea.
> Family members thought it was a good idea to, could read info when they visited.
> Haematologist thought own diary was a good idea
> Family members and the outreach nurse thought the diary was useful

What the clients said!

What section of the Diary do you think was most helpful to you for communicating with others about your health care needs?

> ***Personal Details***
> Extremely helpful

> ***Medication***
> Most Important
> A little helpful not enough pages (I had a medication print out from local GP)
> Useful but forgot to update when medications changed

> ***Tests /Appointments***
> Most important
> Yes, this was the best part

> ***Communication***
> Most Important
> Extremely helpful

> ***Useful Contacts***
> Helpful

> ***Dictionary***
> Excellent used the dictionary to check meanings of ascites and metastases. Daughter referred to the dictionary
> Looked at it as there were some things that we were not sure of
> Did not look at it

Diary recommendations

Suggested Recommendations:

- **Recommendation 1:** A process is developed to ensure clients receive their diary as soon as practicable following diagnosis.
- **Recommendation 2:** Additional medication, communication, tests and appointments pages are added to the dairy.
- **Recommendation 3:** The picture on the front cover of the diary is changed to a picture applicable for the Mid North area, before the diaries are printed again.
- **Recommendation 4:** A page for Doctors to write on is included in the dairy.
- **Recommendation 5:** A weight page to be included in the dairy

Evaluation

“After Hours Support for Regional Primary Health Care Professionals”

Seven Primary Health Care professionals responded with key findings that the flow chart was easy to follow and the primary health care professionals felt supported in their role of caring for palliative care clients by having access to the flow chart.

Evaluation

"In Home Management Plan"

Health professionals were surveyed on the use of the *In Home Management Plan*.

This component of the evaluation was unable to be completed due to there being no current clients using an *In Home Management Plan*.

Two health professional did respond stating that it was inconvenient having to photocopy the form each time it was updated and they were not sure if any of the clients or carers referred to the form.

Evaluation

Mid North Palliative Care Resource Guide:

Ten primary care providers responded .Key findings being that the clinical pathways were the most beneficial part of the Resource Guide. Due to the low numbers of palliative care clients in the Mid North Area only half who responded had used the Resource Guide. Those that had used the resource guide responded that the most useful section was the clinical pathways.

The primary health care professionals reported that they felt supported in their role of caring for palliative care clients by having the flow charts to refer to.

The limitation of the results were due to :

- Not all primary health care professionals were familiar with and/or had used the tool
- Only two of the respondents had accessed the flow chart.

Unexpected project outcomes

The General Practitioner email discussion group and consumer advisory group were not part of the original funding application.

These were unexpected developments and could have been considered at the time of the application, as they contributed to the success of the project.

Sustainability

- Sustainability of this project has been ensured with many strategies. These strategies include the endorsement of the Memorandum of Understandings
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- The "*Mid North Palliative Care Resource Guide"* is designed to be a "working folder" and any additional flow charts/pathways would be updated and an annual review process will be occurring of the Mid North Palliative Care Resource Guide folder and resources by the Port Pirie Palliative Care Service staff.

- Palliative care volunteers have been trained in assisting patient's carer's to complete sections in the diary if required.

Sustainability

- 1000 reprinted patient dairies have been purchased and are available for distribution to cancer support/palliative care patients in the Mid North health area as required. A wire binder was purchased so that additional pages could be added to the diary and a procedure developed to add additional pages to the diary if required.

Words of wisdom to share.

- Evaluation plan needs to be developed early in the project commencement phase.
- Ethics approval applications should be submitted for approval as soon as possible to prevent any project delays.
- Use members of the steering committee to follow up on actions designated to other people to ensure that it has occurred in timeframe required.
- Networking with other Palliative Care team and services to improve knowledge, share experience and resources is important.

Words of wisdom to share.

The Consumers perspective in this type of project is vital and there is a need to establish a participation strategy to enable consumer involvement in all planning and development aspects of service development.

At a National level to consider producing a client held resource based on the Palliative care *“Patient Diary”* available for all newly diagnosed cancer patients or those diagnosed with a terminally illness. The diary would need to be provided free of charge or affordable for all.

Other factors contributing to project success.

- The Project officer was part of the Port Pirie Palliative Care team.
- The project was managed by the Port Pirie palliative care coordinator throughout the project
- The support and guidance of the national evaluation team was vital.
- The consultation and participation with key stake holders, health professionals, clients and carers .
- The formation of the past carers consumer group

A BIG THANKYOU TO ALL INVOLVED IN THE PROJECT .

SPECIAL MENTION TO JANE KEELEY

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