Opening Statement to the Oireachtas Committee on the Future of Healthcare
John Dunne, Chief Executive, Family Carers Ireland – 9th November, 2016

1. Chairperson and Members of the Committee, thank you for the opportunity to be here today. I want to begin by endorsing the findings of Long Term Care Report. In my statement I will elaborate on Family Carers Ireland's submission to the committee which I know you received last July.

2. Family carers enable and underpin most major components of our current health strategy from hospital discharge to treatment of chronic care in the community. And I have no doubt that whatever strategy the Committee proposes, family carers will be a cornerstone of its implementation and success.

3. There is a major discrepancy in the Irish health care system between the way the care for people with acute illnesses and those with a slow debilitating illness is funded. The HSE spent €11 million less on home care in 2015 (€320m) than in 2008 (€331m), despite a 25% increase in the population aged over 65 years. During the same period however, the HSE increased spending on long-term care from €920m to €988m. Moreover, funding for nursing home care is available on a statutory basis but there is no equivalent provision in respect of funding for home care.

4. Primary healthcare must be placed at the heart of Ireland's health service with a view to moving towards a goal-oriented approach to treating chronic conditions in the community. In order to underpin this Family Carers Ireland calls for the establishment of a community based model of care, which recognises the importance of care in the home to our health system and gives statutory entitlement to home care services, including respite.

5. The immediate focus should be framed around ensuring consistency across 90 Primary Care networks[1] within 3-5 years, with the full roll-out of a consistent network of 542 primary care teams[2] being completed within a 6-10 year timeframe. Staff interests should be fully engaged in discussions about how this is to be achieved but we make no apology for proposing that one of the overriding principles for this process should be that in the final analysis their interests must come second to the interests of patients.

[1] Community Health Organisations – Report and Recommendations of the Integrated Service Area Review Group (2014)
[2] Primary Care – A New Direction (2001)

6. Links between primary and secondary care remain as they were characterised in 2010 to the Joint Committee on Health and Children as "poor, resulting in disjointed and uncoordinated care pathways, with less than optimal results for patients"[3]. Despite the HSE's 'practical guide for discharge and transfer from hospital', patients are routinely discharged from hospital without a documented care plan or the necessary supports. Carers' experience is that a brief conversation in a hospital corridor is the limit of engagement with a care plan. FCI believes a formal 'Transfer of Care' protocol would prevent hospitals 'dumping' patients on the community care system.

7. The current approach to the much needed reorientation to primary care seems to be focussing on transposing a problem-oriented acute care model from the hospital to a community setting, thereby limiting the potential of what might be achieved to a mere reconfiguration rather than a re-imagining of our health service. The acute hospital care model is not particularly suited to chronic illnesses usually characterised by co-morbidities and long-term, indeterminate palliative care pathways. A shift to primary care should enable a shift towards a goal-oriented approach to treating chronic conditions in the community. This approach "is well suited to a greater variety of health care issues, is more compatible with a team approach, and places a greater emphasis on physician-patient collaboration".[4] Benefits of this approach include: focus on the person; better balance between clinical and social care considerations; improved approach to co-morbidity and treatment of rare diseases (which account for the 3rd most common condition in Europe); treatment of chronic conditions and conditions like incontinence.

8. Related to the shift to Primary Care is the question of shared responsibility. Family carers welcome the Amárach[5] findings that the wider public recognise or would like to see a vision of shared responsibility between State, Family and other actors. At present all gaps in care supports (state or otherwise) fall back on families, even at a cost to carers' health and wellbeing. Family carers' experience is that their expertise and practical knowledge of the patient is not taken into account by health professionals. Carers are often not involved in care planning. Care planning should be viewed as something to be negotiated between health professional, patient and carer.

9. The lack of clarity in sharing responsibility for healthcare between the state and family/community is only reinforced by the prevailing situation in which HSE acts as commissioner, provider and regulator in the home care sector. It represents a significant complicating factor in any move towards a self-directed support model of Home Care which is about to begin piloting with a view to national roll-out in 2018. This situation is not entirely of the HSE's making and it needs to be addressed as a matter of urgency on a statutory rather than administrative basis. It is only as part of clarifying formal responsibility for various elements of the healthcare system that it will be possible to decide whether or not it makes sense to have home care formally regulated by HIQA rather than overseen by an ombudsman-type model, for example.

[3] Joint Committee on Health and Children Second Report on Primary Medical Care in the Community (2010)
[4] Mold JW, Blake GH, Becker LA (1991) Goal-oriented medical care, *Family Medicine* 23(1):46-51.
[5] Amarach Public Opinion Survey on Long Term Care conducted between 9th and 13th of May 2016.
http://www.thirdageireland.ie/assets/site/files/pr/Am%C3%A1rach_Public_Opinion_Survey_LTC_FINAL_150616.pptx

10. The required shift to Primary Care will increase the system's dependence on a hidden workforce of 200,000 plus family carers on which Ireland's Healthcare system depends. This dependence will only grow in coming years – today one in twenty people in Ireland is a family carer – by 2030 demographic changes will require one in five of us to undertake this role just to maintain current levels of service. Social and economic considerations will compound this situation.

11. The economic case for safeguarding family care into the future is clear given that family carers provide some 6.2 million hours of unpaid care each week saving the State over €4 billion each year in avoided health and social care costs. [6] Economics aside, it is socially and political significant that a majority of Irish people want to play a significant role in the care of their loved ones when they fall ill and that they want a health system that will support them in this role.[7]

12. Based on our current experience of supporting family carers[8] we would recommend the following proposals to the committee if this challenge to **grow family caring in line with wider demographic changes**:

    - Information campaign to promote earlier self-identification by family carers as a key to better, more sustainable care situations;
    - Integrated information, training and peer networking supports for family carers readily available in each Primary Care network area;[9]
    - Carer assessment based on validated well-being scales[10] and appropriate interventions to assist family carers who are being overwhelmed by their particular circumstances;
    - Availability of appropriate home care services along with person-centred and flexible respite options;
    - Guaranteed access to appropriate respite options and provision for orderly planning and transition when a family carer becomes incapable of sustaining their caring role;
    - Proper facilities to support the health and well-being of family carers themselves including screening, respite cover for medical procedures and medical cards for full-time carers in receipt of the Carers Allowance;
    - Additional measures to support people balancing a family care role and paid employment.

13. Such measures should be planned and implemented in the context of the ongoing renewal of the **National Carers' Strategy** on a rolling 4 year basis. In time this ought to be underpinned by a Carers Act, similar to that enacted in Scotland (2016).

14. In conclusion:

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[6] This is a conservative estimate based on average hours worked according to Census 2011 and €12 per hour replacement care cost rate which reflects pay cost only with no allowance for ancillary costs.

[7] Amarach Public Opinion Survey on Long Term Care conducted between 9th and 13th of May 2016. http://www.thirdageireland.ie/assets/site/files/pr/Am%C3%A1rach_Public_Opinion_Survey_LTC_FINAL_150616.pptx

[8] National Carers' Strategy (2012) defines a Family Carer as '*someone providing an ongoing significant level of care to a person in need of that care in the home due to illness or disability or frailty*'.

[9] Training options to include a foundation 'Caring with Confidence' course; short technical courses on patient moving and handling; nutrition and hydration; wound care etc; and more advanced courses such as 'Caring for Progressive Life-limiting Conditions'

[10] CES/ASCOT – CSAR or InterRAI whilst important as resource allocation tools are not really capable of fulfilling this role.

- Family Carers Ireland supports placing primary care at the heart of Ireland's health service with a view to moving towards a goal-oriented approach to treating chronic conditions in the community;
- In order to underpin this FC calls for the establishment of a community based model of care, which recognises the importance of care in the home to our health system and gives statutory entitlement to home care services, including respite.
- Any long term strategy must address the question of restructuring and redistribution of resources and the reorientation of these to support care in the home and community. It is critical that this committee's final report contributes to framing an analysis and strategy in regard to this challenge not least because there is a growing legitimation crisis in regard to the state's capacity to justify additional health spending.