A Guide to Cancer for Health Service Providers
“We receive all patients with a smile. They want a compassionate face more than the medication you give them.”

Health Worker
Acknowledgments

This reference guide was prepared by the Johns Hopkins Center for Communication Programs and Qayana Communication PLC in collaboration with the Federal Ministry of Health in Ethiopia with support from the American Cancer Society. Representatives from cancer organizations in Ethiopia provided technical guidance and designed the reference guide content based on qualitative research among cancer patients and their caregivers. Some content in the reference guide is an adaptation from materials prepared by the American Cancer Society. In addition, limited content was adapted from MacMillan Cancer Support and the U.S. National Cancer Institute. A complete list of sources can be found at the end of this guide in the reference section.

MADO Communication PLC was responsible for graphic design and illustrations.

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“That is what we need the most, we need to learn how to counsel and how to educate patients.”

Health Worker
Introduction

This guide is designed to address gaps in knowledge among nurses and other health service providers who care for cancer patients. It is divided into three chapters: Counseling the Cancer Patient, Understanding the Disease of Cancer, and Helping Patients Manage Side Effects. Each of the chapters responds to issues raised by cancer care providers during discussions held in Spring 2016. These providers talked about the many challenges of providing cancer treatment, care, and support in Ethiopia. Some of their reflections are shared in these pages. In addition to this reference guide, we have also developed three supporting materials entitled, ‘After Diagnosis’, ‘Listening With Your Heart’, and ‘Counseling Guide for Cancer Patients’.

This guide is written in recognition of the hard work and dedication of all health service providers who treat cancer patients. We applaud you for the unreserved care and support you provide to cancer patients in their time of greatest need. Every day, what you do and say makes a difference in the lives of patients who face one of the world’s most difficult diseases.
Chapter 1: Counseling the Cancer Patient

Good communication with patients and caregivers is very important in cancer care, and can help patients:

- Understand their diagnosis;
- Deal with fear and anxiety;
- Be more satisfied with care and feel more in control;
- Understand and follow through with treatment;
- Adopt a healthy lifestyle;
- Have a better quality of life;
- Be informed.

Poor communication can lead to failure to follow treatment, negative patient outcomes, an increase in a patient’s anxiety, and feelings of vulnerability and powerlessness.

This chapter explains the key steps in the counseling process and tips for counseling cancer patients.

The GATHER Process for Counseling

The GATHER process is a time-tested process for counseling used all over the world. This process can be used in many settings and for many health topics, including cancer counseling. The six key steps of Greet, Ask, Tell, Help, Explain and Return are explained here:
Greet
The first step of the process is greeting each patient in a friendly, respectful manner and with a smile. Acknowledge that this is a difficult time for the patient and their family.

Be sure to:
- Inform patients that the session is confidential and you will not repeat what they have said, or any information about them, to others.
- Provide a private space for counseling and examinations. Put away mobile phones, turn off computers, and close the door.
- Make sure you’re at the same level as the patient – don’t stand up if they are sitting down.
- Be aware of your attitude toward the patient. Do not assume that a person of low literacy cannot understand the information. Instead, recognize that you may need to take a few extra minutes to explain the situation clearly.

Ask
This second step focuses on asking questions and encouraging patients to talk. Be sure to:
- Use a tone of voice that shows interest, concern, and friendliness.
– Pay attention to what you see – the patient’s facial expression and body language.
– Avoid asking questions that can be answered with a “yes” or “no.” Instead focus on questions that start with “how” or “what” so that patients can explain themselves.
– When you must ask a delicate question – for example, asking about sexual life -- explain why it is important to have the information.
– Avoid asking “why.” It can sound like you are finding fault.

Tell
Once you have asked about the patient’s concerns, give them the information they need. Be sure to:
– Use the Counseling Guide for Patients and their Caregivers to explain testing and staging, treatment, side effects, and coping.
– Use words that patients can understand.
– Explain how to navigate the system at referral hospitals.

Help
Cancer patients need a lot of help - signing up for treatment, paying for services, letting others know about the cancer. Help patients find solutions for their problems. Be sure to:
- Use the resources at the back of this guide to help with paying for medicine or shelter.
- Use the *Counseling Guide for Patients and their Caregivers* to help with coping and communication.
- Encourage them to have firm hope while waiting to be admitted for chemo or radiation therapy.
- Write down any important information to help them remember details later.

**Explain**

This step focuses on clarifying information and increasing understanding. Repeat the instructions you expect them to do or recall in simple language. Be sure to:

- **Keep it short.** Choose the few most important points that the client must remember.
- **Keep it simple.** Use short sentences and common words that clients understand.
- **Put first things first.** Give the most important information first. It will be remembered best. Focus on the most important pieces.
- **Repeat.** At the end of your session, remind the client of the most important instruction.

Be sure to give the ‘After Diagnosis’ booklet to patients and the ‘Listen with Your Heart’ booklet to caregivers to take home with them.
Return
Once you finish your discussion with the client, smile and tell them when to come back for their next appointment. Encourage them to bring a caregiver with them when they return. Making the client feel welcome to come back is as important as making the client feel welcome the first time.

Tips for Counseling Cancer Patients

When to Communicate with Cancer Patients
Communication is important throughout cancer care, but especially when important decisions are to be made. These important decision times include:

- When the patient is first diagnosed.
- Any time new decisions about treatment need to be made.
- After treatment, when discussing how well it worked.
- Whenever the goal of care changes.

Breaking Bad News
The following steps to breaking bad news about cancer are helpful:

- Prepare well. Know all the facts before meeting the patient/caregiver.
- Find out how much the patient already knows. You can ask, “Can you bring me up to date on your illness and how things are now?”
– Check that the patient/caregiver wants more information and how much more. You can say, “We have more results now. Would you like me to give you an update on what we know? I will go step by step and you can stop me whenever you want.”

– Indicate that the information to be given is serious. You can say, “I am afraid it looks rather serious,” and then allow a pause for the patient to respond.

– Allow patients to express their feelings.

– Listen to concerns and ask questions. You can say, “What are your main concerns at the moment?” or “What does this mean to you?”

– Wind down the session by summarising issues that are raised and plan the next steps.

– Make yourself available to discuss the illness further, as needed.

**Doing the Best You Can**

Communication takes time. It is challenging to counsel patients when you have many patients to see and many demands on your time. Patients will appreciate any time you can give them. Greeting each patient respectfully, answering a question or two, and offering even a small piece of advice can vastly improve a patient’s state of mind.
“We do reassurance regarding cancer through counseling. When they come here they give up hope, they feel sad; because the hospital admission by itself creates stress on them so we try to console them. We create a comfortable environment. We give them counseling service as much as we can.”

Health Worker
Chapter 2: Understanding the Disease of Cancer

Cancer is not just one disease. There are many types of cancer. Cancer can start in the lungs, the breast, the colon, or even in the blood. Cancers are alike in some ways, but they are different in the ways they grow and spread.

Cancer cells differ from normal cells in the way they grow and spread. While the cells in our bodies are specialized and have specific functions, cancer cells do not. This is one of the reasons why cancer cells can continue to divide without stopping. Additionally, normal cells divide in an orderly way and die when they are worn out or damaged, and new cells take their place. However, cancer cells ignore the signals that tell normal cells to stop dividing - making them grow out of control.

When cancer cells keep growing and making new cells, they crowd out normal cells causing problems in the part of the body where the cancer started. Most cancers form a lump called a tumor or a growth. But not all lumps are cancer. Lumps that are not cancer are called benign. Lumps that are cancer are called malignant. There are some cancers, like leukemia (cancer of the blood), that don’t form tumors. They grow in the blood cells or other cells of the body.
Cancer cells may be able to influence the normal cells and blood vessels that surround and feed a tumor. For instance, they can cause nearby normal cells to form blood vessels that supply tumors with oxygen and nutrients which they need to grow, and remove waste products from tumors. Cancer cells are also often able to avoid the immune system and use it to stay alive and grow.

How Cancer Arises
Cancer is a disease of abnormal gene function. Genes are pieces of DNA (deoxyribonucleic acid) that contain the instructions on how to make the proteins the body needs to function, when to destroy damaged cells, and how to keep the cells in balance. Genes control things such as hair color, eye color and height, and can also affect the chance of getting certain diseases, such as cancer.

An abnormal change in a gene is called a mutation. Mutations can either be inherited or acquired. An inherited gene mutation is present in the egg or sperm that formed the child and so can be passed on to the next generation, while an acquired mutation occurs some time later in life and cannot be passed on to the next generation. While some acquired mutations can be caused by environmental exposure, such as cigarette
smoke, radiation, hormones, and diet, others have no clear cause, and seem to occur randomly as the cells divide. An acquired mutation occurs in one cell, and then is passed on to any new cells that are the offspring of that cell. Most cancers are caused by acquired mutations.

**Oncogenes and tumor suppressor genes**

Two of the main types of genes that play a role in cancer are oncogenes and tumor suppressor genes.

Proto-oncogenes are genes that help cells grow and divide. When a proto-oncogene mutates it can become permanently turned on or activated when it is not supposed to be. When this happens, the cell grows out of control, which can lead to cancer. This is then called an oncogene.

Tumor suppressor genes are normal genes that slow down cell division, repair DNA mistakes, or tell cells when to die (a process known as *apoptosis* or *programmed cell death*). When tumor suppressor genes don’t work properly, cells can grow out of control, which can also lead to cancer.

An important difference between oncogenes and tumor suppressor genes is that oncogenes result from the *activation* (turning on) of proto-oncogenes, but tumor suppressor genes cause cancer when they are *inactivated* (turned off).
**When Cancer Spreads**

Metastatic cancer is a cancer that has spread from the part of the body where it started (the primary site) to other parts of the body. When cancer cells break away from a tumor, they can travel to other areas of the body through the bloodstream or the lymph system (a collection of vessels that carry fluid and immune system cells).

Cancer cells have to go through several steps to spread to new parts of the body:

- They have to be able to break away from the original tumor and enter the bloodstream or lymph system, which can carry them to another part of the body.
- They need to attach to the wall of a blood or lymph vessel and move through it into a new organ.
- They need to be able to grow and thrive in their new location.
- They need to be able to avoid attacks from the body’s immune system.

Going through all these steps means the cells that start new tumors may no longer be exactly the same as the ones in the tumor they started in. This may make them harder to treat.
Even when cancer has spread to a new area, it’s still named after the part of the body where it started. Treatment is also based on where the cancer started. For example, if prostate cancer spreads to the bones, it’s still prostate cancer, not bone cancer, and the doctor will recommend treatments that have been shown to help against metastatic prostate cancer. Likewise, breast cancer that has spread to the lungs is still breast cancer, not lung cancer, and is treated as metastatic breast cancer. Metastatic tumors can severely damage body functions, and most people who die of cancer die of metastatic disease.

**Types of Cancer**

There are more than 100 types of cancer. Types of cancer are usually named for the organs or tissues where the cancers form. In the year 2012, over 14 million new cancer cases occurred worldwide and 32.5 million previously diagnosed cancer patients were still living. Approximately 61,000 of new cancer cases were registered in Ethiopia the same year. While the rates of survival in Ethiopia are low, the Federal Ministry of Health is taking many important steps to improve screening, diagnosis, and treatment at regional centers to improve the outcome for cancer patients.
Risk factors

Age
Tobacco smoke
Excessive alcohol consumption
Chronic inflammation
Unhealthy diet
Immunosuppression
Infectious agents (HIV, HPV and H. Pylori)
Obesity
Excessive Sunlight
**Risk factors**

Cancer is a complex group of diseases with many possible causes. While some types of cancer run in certain families, most cancers are not clearly linked to the genes we inherit from our parents but rather attributed to risk factors such as exposure to chemicals or other substances, infections, as well as certain behaviors.

Limiting exposure to avoidable risk factor such as cigarette smoking may lower the risk of developing certain cancers, but risk factors such as age and family history cannot be controlled. The following are the most studied known or suspected risk factors for cancer.

It is worth noting that many people with risk factors never get cancer, and many people who have cancer do not have any risk factors. However, cancer happens more often among people who have risk factors than those who do not.

**Signs and Symptoms**

Cancer is a group of diseases that can cause almost any sign or symptom. The signs and symptoms will depend on where the cancer is, how big it is, and how much it affects the organs or tissues. If a cancer has spread (*metastasized*), signs or symptoms may appear in different parts of the body.
The most common signs and symptoms include:

Unexplained weight loss
Fever
Fatigue
Pain
Skin changes
Change in bowel habits or bladder function
Sores that do not heal
White patches inside the mouth or white spots on the tongue
Unusual bleeding or discharge
Thickening or lump in the breast or other parts of the body
Indigestion or trouble swallowing
Recent change in a wart or mole or any new skin change
Nagging cough or hoarseness
Cancer screening
Cancer screening is done to catch cancer early – either while the cells are still precancerous or before they have a chance to spread to other parts of the body and are still treatable. Ethiopia’s national cancer control program includes screening for breast and cervical cancer. Screening of breast cancer in Ethiopia is predominately done through promotion of breast self-examination as well as clinical breast examination of all women above 18 years old that come to a health institution. Cervical cancer screening is done using VIA (visual screening using acetic acid) to detect pre-cancerous cervical lesions among non-symptomatic women aged 30-49 every five years.

Diagnostic Tests
Doctors use different types of exams and tests to figure out a cancer’s stage. Depending on where the cancer is located, the physical exam may give some clue as to how much cancer there is. Imaging tests like X-rays, CT scans, MRIs, ultrasound, and PET scans may also give information about how much and where cancer is in the body.

A biopsy is often needed to confirm a cancer diagnosis. Biopsies might also be needed to find out if an abnormal spot seen on an imaging test is really cancer spread. During a biopsy, the doctor removes a tumor or pieces of a tumor to be looked at under a microscope. Some
biopsies are done during surgery. But with many types of biopsies, the doctor removes small pieces of tumor through a thin needle or through a flexible lighted tube called an endoscope.

**Staging**

Staging is done when a person is first diagnosed, before any treatment is given. The main types of staging are clinical staging and pathological staging. Clinical staging is an estimate of the extent of the cancer based on results of physical exams. The clinical stage is a key part of deciding the best treatment to use and is also used as the baseline for comparison when looking at how the cancer responds to treatment. If surgery is being done, doctors can also determine the pathologic stage (also called the surgical stage) of the cancer.

**Staging systems**

There are different types of staging systems, but the most common and useful for most types of cancers is the TNM system. In the TNM system, each cancer is assigned a letter or number to describe the tumor, lymph nodes, and metastasis.

- **T** stands for the original (primary) **tumor**.
- **N** stands for **nodes**. It tells whether the cancer has spread to the nearby lymph nodes.
- **M** stands for **metastasis**. It tells whether the cancer has spread to distant parts of the body.
The **T** category gives information about aspects of the original (primary) tumor, such as its size, how deeply it has grown into the organ it started in, and whether it has grown into nearby tissues.

**TX** means the tumor can’t be measured.

**T0** means there is no evidence of a primary tumor (it cannot be found).

**Tis** means that the cancer cells are only growing in the most superficial layer of tissue, without growing into deeper tissues. This may also be called *in situ* cancer or *pre-cancer*.

Numbers after the T (such as **T1, T2, T3, and T4**) might describe the tumor size and/or amount of spread into nearby structures. The higher the T number, the larger the tumor and/or the more it has grown into nearby tissues.

The **N** category describes whether the cancer has spread into nearby lymph nodes.

**NX** means the nearby lymph nodes cannot be evaluated.

**N0** means nearby lymph nodes do not contain cancer.

Numbers after the N (such as **N1, N2, and N3**) might describe the size, location, and/or the number of nearby lymph nodes affected by cancer. The higher the N number, the greater the cancer spread to nearby lymph nodes.
The M category tells whether the cancer has spread (metastasized) to distant parts of the body.

**M0** means that no distant cancer spread was found.

**M1** means that the cancer has spread to distant organs or tissues (distant metastases were found).

Some cancer types have their own version of this classification system, so letters and numbers don’t always mean the same thing for every kind of cancer.

**Stage grouping**

Once the values for T, N, and M have been determined, they are combined to assign an overall stage. For most cancers, the stage is a Roman numeral from I to IV, where stage IV (4) is the highest and means the cancer is more advanced than in the lower stages.

Stage 0 is *carcinoma in situ* for most cancers. This means the cancer is at a very early stage, is only in the area where it first developed, and has not spread. Not all cancers have a stage 0.

Stage I cancers are the next least advanced and often have a good prognosis (outlook). The outlook is usually not as good for higher stages.

**Other staging systems**

Not all cancers are staged using the TNM system. Some cancers grow and spread in a different way. For
example, many cancers in or around the brain are not staged using the TNM system, since these cancers tend to spread to other parts of the brain and not to lymph nodes or other parts of the body. Staging systems other than the TNM system are often used for Hodgkin disease and other lymphomas, too, as well as for some childhood cancers.

**A cancer’s stage does not change**

An important point to remember is that the stage of a cancer is determined only when (or soon after) the cancer is diagnosed. This stage does not change over time, even if the cancer shrinks, grows, spreads, or comes back after treatment. The cancer is still referred to by the stage it was given when it was first found and diagnosed, although information about the current extent of the cancer is added (and of course, the treatment is adjusted as needed).

For example, let’s say a woman is first diagnosed with stage II breast cancer. The cancer goes away with treatment, but then it comes back and has spread to the bones. The cancer is still called a stage II breast cancer, now with recurrent disease in the bones. If the breast cancer did not go away with the original treatment and spread to the bones it would be called a stage II breast cancer with bone metastasis. In both cases, the original stage does not change and it’s *not* called a stage IV
breast cancer. Stage IV breast cancer refers to a cancer that has already spread to a distant part of the body when it’s first diagnosed.

**Cure and Remission**

To be cured means that there are no traces of cancer after treatment and it is possible the cancer will never come back. Remission means that the signs and symptoms of cancer are reduced. Remission can be partial or complete. In a complete remission, all signs and symptoms of cancer have disappeared. If the patient remains in complete remission for 5 years or more, then some doctors may say they are cured.

**Types of Treatments**

There are many types of cancer treatment. The major treatments include: surgery, chemotherapy, radiation, hormonal therapy, targeted therapy, immunotherapy, stem cell transplant and precision medicine. Currently, available treatment options in Ethiopia are surgery, chemotherapy, hormonal therapy and radiation therapy.
Chapter 3:
Helping Patients Manage Side Effects

Counseling on Diet and Nutrition
Most of the time, cancer patients can eat any food they wish as long as it is prepared in a hygienic and safe manner. It is important to eat a variety of food every day. Advise patients to eat a balanced diet, including:

- Proteins – shiro, meat, eggs, chicken, fish, milk, lentils, beans, chickpeas
- Carbohydrates - injera, bread, potatoes, corn, oats, wheat, and barley
- Fruits and vegetables - tomatoes, kale, spinach, salads, oranges, bananas, and papaya
- (See food chart below for more details)

Also advise patients to:

- Be sure to get enough protein.
- Eat smaller meals to aid digestion instead of three large meals a day.
- Avoid alcohol, tobacco, and Khat.
- Drink at least 8 glasses of water every day.
- Make sure to wash your hands after using the latrine and before preparing and eating foods.
Ask patients if they have a problem with their appetite. There are medications that can help increase appetite.
Coping with side effects of cancer treatment

Many cancer treatments cause side effects. Helping patients manage side effects is an important part of patient care. Here are some common side effects and ways to relieve them.

**Fatigue:** Most patients struggle with fatigue that is caused both by treatment and the disease itself. Counsel patients to:
- Save their energy for only the most important tasks.
- Set up and follow a structured daily routine. Do things slowly and ask for help.
- Eat a balanced diet and drink about 8 to 10 glasses of water a day (unless a special diet is prescribed).

If the patient is having problems sleeping, then advise them to:
- Use their bed only for sleep and sex. Do not read or watch TV in bed.
- Limit daytime naps to early in the day, not near bedtime.
- Think and talk about worries and fears early in the daytime.
- Don’t drink alcohol, coffee and other caffeinated drinks near bed time; instead take warm milk with honey.
- Go to bed when they feel sleepy and always go to bed at the same time.
- Have someone give them back rubs or massage their feet before bedtime.
- Make sure their sleeping area is quiet and dark.

**Diarrhea:** Diarrhea is common during cancer and has many causes - chemotherapy, radiation therapy, infections and tumor. Advise patients to:

- Eat salty foods, such as broths and soups; potatoes with the skin; and bananas, fruit juices, cooked carrots, white rice, yoghurt.
- Avoid milk and foods that are sweet, hot or spicy. Also avoid alcohol or coffee, acidic drinks such as tomato juice and citrus juices.
- Drink at least one cup of liquid after each loose bowel movement.
- Clean their bottom with a mild soap after each bowel movement, rinse well with warm water, and pat dry. Apply a water-repellent ointment or petroleum jelly and wash hands with soap after using the toilet and before preparing or eating food.

Explain to patients it is important for them to come back to see you if they experience:
– Diarrhea or stomach pain for more than a day
– Dizziness or feeling like they could pass out
– Stools with an unusual odor or color
– Blood in or around the rectum or in the stool
– Loss of five or more pounds after the diarrhea starts
– Not passing urine for 12 or more hours
– Unable to take fluids for 2 or more days
– Fever of 38°C or higher (taken by mouth)
– Constipation followed by small amounts of diarrhea or oozing of liquid stool.

**Nausea and vomiting:** Nausea and vomiting are common side effects. To minimize these effects, advise patients to:

– Eat foods that are easy to digest on days when they are getting treatment
– Wear loose-fitting clothes
– Limit sounds, sights, and smells that cause nausea and vomiting
– Eat small meals or snacks throughout the day rather than 3 large meals
– Keep their mouth clean; brush teeth and rinse mouth out every time they vomit.

Let patients know there are anti-nausea/vomiting medicines if they have severe nausea or vomiting.
**Sore mouth:** Patients can help relieve this symptom by:

- Brushing their tongue, gums, top of their mouth, and teeth with a soft toothbrush within 30 minutes after eating and at bedtime.
- Brushing teeth with a soft brush every morning and night.
- Eating a well-balanced diet.
- Staying away from spicy foods, very hot or very cold foods, and hard or crunchy foods.

If the mouth bleeds, put pressure on the site with a cloth dipped in ice water or rinse mouth with ice water, if available.

**Temporary hair loss:** Some chemo medicines and radiation can cause hair loss. Let patients know they might lose the hair on their head, face, arms, legs, underarms, or the pubic area between their legs over night or gradually. Usually, hair will grow back after the treatment is completed. Until then, suggest that they cover their head with a scarf, cap or wig.

**Change in sexual desire:** Some medicines cause hormonal changes in women that cause hot flashes and vaginal dryness. Both men and women often lose their desire for sex during treatment. Encourage patients to talk with their marital partner or lover about this issue.
Let them know they can find pleasure in physical intimacy by hugging, touching, holding, and cuddling without sex. Advise them on whether it is ok to have sex during treatment.

**Fertility problems:** Some types of treatment can cause problems with fertility. Cancer treatment can also cause birth defects. Doctors recommend that both men and women use a family planning method during treatment and for some time after treatment ends. Women may find that their periods become irregular or stop while getting treatment. However, it may still be possible to become pregnant, so family planning is still needed. Be sure to offer and provide birth control to avoid pregnancy during treatment.
Take good care of yourself, too!

Taking care of cancer patients is very stressful. It’s important to take good care of yourself, just as you take good care of your patients!

Be sure to spend some time every day doing something you enjoy – a hobby, taking a walk, talking with friends, or anything that brings you joy. It will keep you from becoming stressed out.

As terrible as cancer is, we can take encouragement knowing that our words and actions help ease the pain and suffering of patients. Just answering a patient’s questions provides an important measure of comfort.

Remember, we cannot change the outcome for our patients, but we can make their journey a little easier. The care and kindness we show to patients will always be remembered.
Reference


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<td><strong>Mathiwos</strong>&lt;br&gt;Wondu&lt;br&gt;YeEthiopia&lt;br&gt;Cancer Society</td>
<td>Shelter, food, transportation and support</td>
<td>01-16-39-47-60&lt;br&gt;01-18-12-28-38</td>
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<tr>
<td><strong>YeEthiopia</strong>&lt;br&gt;Cancer Association</td>
<td>Shelter, food, transportation and support</td>
<td>01-12-59-14-76&lt;br&gt;09-11-24-86-80</td>
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<td><strong>Cancer Care</strong>&lt;br&gt;Ethiopia</td>
<td>Shelter, food, transportation and support</td>
<td>01-13-20-11-52&lt;br&gt;09-38-88-88-80</td>
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